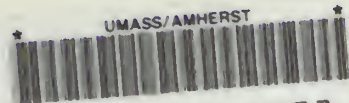


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**THE STATUS OF PEOPLE WITH BRAIN INJURIES IN MASSACHUSETTS:**  
**Epidemiological Aspects and Service Needs**



**Massachusetts Rehabilitation Commission**  
**Statewide Head Injury Program**



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THE STATUS OF PEOPLE WITH BRAIN INJURIES IN MASSACHUSETTS:  
EPIDEMIOLOGICAL ASPECTS AND SERVICE NEEDS

MASSACHUSETTS REHABILITATION COMMISSION  
STATEWIDE HEAD INJURY PROGRAM

MAY, 1988





THE COMMONWEALTH OF MASSACHUSETTS  
MASSACHUSETTS REHABILITATION COMMISSION

MICHAEL S. DUKAKIS, GOVERNOR  
PHILIP W. JOHNSTON, SECRETARY, EXECUTIVE OFFICE OF HUMAN SERVICES  
ELMER C. BARTELS, COMMISSIONER  
MASSACHUSETTS REHABILITATION COMMISSION

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THE STATUS OF PEOPLE WITH BRAIN INJURIES IN MASSACHUSETTS:  
EPIDEMIOLOGICAL ASPECTS AND SERVICE NEEDS

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MASSACHUSETTS REHABILITATION COMMISSION  
INDEPENDENT LIVING DIVISION  
STATEWIDE HEAD INJURY PROGRAM  
20 PARK PLAZA  
BOSTON, MA 02116

MAY, 1988

A REPORT PREPARED FOR THE MASSACHUSETTS STATE LEGISLATURE  
HOUSE WAYS AND MEANS COMMITTEE  
SENATE WAYS AND MEANS COMMITTEE



## ACKNOWLEDGEMENTS

THE STATUS OF PEOPLE WITH BRAIN INJURIES IN MASSACHUSETTS: EPIDEMIOLOGICAL ASPECTS AND SERVICE NEEDS is the first comprehensive study done in Massachusetts on the presenting conditions and needs of this population. This document represents the cooperative efforts of a number of state agencies and professionals. Many of these individuals deserve a special thanks for their efforts and assistance with this project:

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Kathleen Benjamin, R.R.A., Director of Medical Records, University  
of Massachusetts Medical Center

Geraldine Berenholtz, R.R.A., M.P.H., Consultant

Jean Bush, President, Massachusetts Head Injury Association

Georgia Carpenter, Ph.D., Boston Neurobehavioral Institute

Jennifer Chiavaris, Director, South Bay Community Re-entry

Carla DiScala, Ph.D., Research Associate, Department of  
Rehabilitation Medicine, New England Medical Center Hospital

Larry Finison, Executive Director, Massachusetts Long Term Care  
Foundation

Howard Gold, Director Policy Analysis Unit, New York Office of  
Mental Retardation and Developmental Disabilities

Joan Goldsberry, Director, Spaulding Rehabilitation Hospital Home  
Health Program

Miriam Jost, Manager of Consulting Services, Spaulding  
Rehabilitation Hospital

Kenneth Leary, Project Director, Metro Boston Hospital Council

Nancy Lefkowitz, Director, Speech-Language Pathology, Spaulding Rehabilitation Hospital

Edward McNamara, Director, Central Mass EMS Corp.

Kathy Miller, Office Manager, Massachusetts Head Injury Association

Tricia Minassian, Program Evaluation Coordinator, Spaulding Rehabilitation Hospital

Linda Moriarty, Director, Western Mass EMS Corp.

Phil Morse, Ph.D., Neuropsychology Consultant, Statewide Head Injury Program, Massachusetts Rehabilitation Commission

Margaret Olendzki, Ph.D., Director of Data Analysis, Massachusetts General Hospital

Corrine Palver, National Association of Rehabilitation Facilities, Washington, D.C.

Mary Pepping, Ph.D., Director, Neuropsychological Rehabilitation Program, Presbyterian Hospital, Oklahoma City, Oklahoma

Cindy Rodgers, Director, Statewide Comprehensive Injury Prevention Program, Division of Family Health Services, Massachusetts Department of Public Health

Tony Roman, Director of Data Operations, Center for Survey Research, University of Massachusetts at Boston

Wayne Silva, M.D., Director, University of Massachusetts Trauma Center

Ronald St. Jean, Vice President, Administration and Operations, Health Insurance Association of America

J. Paul Thomas, Ph.D., Director, Medical Sciences Programs,  
National Institute on Disability and Rehabilitation Research

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service delivery in this state.





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CONTRIBUTORS

CAREY AZZARA, M.A.

Assistant Director, Statewide Comprehensive Injury Prevention Program,  
Massachusetts Department of Public Health

DEBRA S. KAMEN, M.S.

Director, Statewide Head Injury Program, Massachusetts Rehabilitation  
Commission

FRANCESCA A. LAVECCHIO, PH.D.

Chief Neuropsychology Consultant, Statewide Head Injury Program,  
Massachusetts Rehabilitation Commission; Director, Boston  
Neurobehavioral Institute; Assistant Professor (Anatomy and Cellular  
Biology), Tufts University School of Medicine; Assistant (Adjunct)  
Professor (Psychiatry), Boston University School of Medicine

THOMAS W. MANGIONE, PH.D.

Senior Research Fellow, Center for Survey Research, University of  
Massachusetts at Boston; Associate (Adjunct) Professor, Boston  
University School of Public Health

DEBORAH POTTER, M.A.

Senior Research Assistant, Center for Survey Research, University of  
Massachusetts at Boston

JULIANNE ZUCK, M.PHIL.

Consultant, Statewide Head Injury Program, Massachusetts  
Rehabilitation Commission





## TABLE OF CONTENTS

	PAGE
EXECUTIVE SUMMARY.....	xiii
INTRODUCTION.....	1
CHAPTER I:     TRAUMATIC BRAIN INJURY: AN OVERVIEW.....	7
CHAPTER II:    STAGES OF RECOVERY: CLIENT PATHWAYS.....	37
CHAPTER III:   AN ANALYSIS OF THE NEEDS OF HEAD INJURY SURVIVORS (TBI): COMMONWEALTH OF MASSACHUSETTS.....	71
CHAPTER IV:    HEAD INJURY: PRIMARY PREVENTION IS OUR BEST HOPE.....	119
CHAPTER V:     NON-TRAUMATIC BRAIN INJURIES: EPIDEMIOLOGICAL ASPECTS AND MAJOR SEQUELAE.....	131
CHAPTER VI:    SUMMARY AND RECOMMENDATIONS.....	187
 APPENDICES:	
APPENDIX A - Survey of Head Injury Survivors and Family Members.....	205
APPENDIX B - Survey of Providers.....	225
APPENDIX C - Current Living Settings.....	239
APPENDIX D - Characteristics of Head Injury Survivors Reported by Providers.....	243
APPENDIX E - Impairment Indicators by Sample Type.....	247
APPENDIX F - Type of Services Needed.....	259
APPENDIX G - Acronym List.....	263



## EXECUTIVE SUMMARY

### INTRODUCTION

This report is being submitted to the Massachusetts Legislature and the Governor in response to a request by the House and Senate Ways and Means Committees to identify the incidence of Massachusetts residents who have survived traumatic head injuries and the corresponding service needs they may require during their lifetimes. A decision was made to include the additional study of those individuals with other forms of acquired brain injury (e.g., anoxic brain damage) because it was thought that the clinical needs of this population would be consistent with those of the traumatically injured group and thereby have serious implications for any recommendations this report would put forth. The study was conducted under the direction of the Statewide Head Injury Program which is administered within the Independent Living Division of the Massachusetts Rehabilitation Commission. This program has had the lead responsibility since July 1, 1985 for coordinating services for Massachusetts residents of any age who have sustained an externally caused traumatic head injury.

### INCIDENCE AND CHARACTERISTICS

Statewide data were accessed from the Uniform Hospital Discharge Data Set (UHDDS) for three consecutive years, 1984-1986. The UHDDS is a mandated reporting system of the Rate Setting Commission which reports all discharges from acute care hospitals in the Commonwealth. During the time period studied, there were approximately 46,000 individuals each year within the Commonwealth who were treated for and diagnosed with various forms of acquired brain damage. Over 23,000 people in this three year period sustained traumatic head injuries and survived while approximately 3.9 percent died during their hospitalization. The majority of head injuries are sustained by males with the highest frequency of injury occurring in the school age population.

Head injury survivors exhibit a wide range of handicapping conditions which compromise an individual's ability to care for him/herself and live independently. Cognitive, physical, behavioral and psychological impairments are seen in varying degrees within this population often resulting in the need for day to day support services. The recovery process and successful community reintegration necessitates multiple services, caregivers and funding sources. Case management is critical to the timely identification, mobilization and coordination of these services and resources.

## NON-TRAUMATIC BRAIN INJURIES

A similar analysis was completed for non-traumatic brain injuries which account for over 37,000 live discharges per year. The service needs exhibited by individuals with these disorders are entirely consistent with those reported by traumatically brain-injured people.

## NEEDS ASSESSMENT

In order to determine more specifically what service needs Massachusetts citizens with traumatic head injuries might have, a statewide survey was distributed to more than 2,000 head-injured people, family members and clinicians. Some of the major findings from this survey are summarized below:

- The leading cause of traumatic head injury is motor vehicle-related crashes
- Less than 20% of those injured were wearing their seat belts
- More than 50% of those who sustained in motor vehicle-related injuries had consumed alcohol or drugs within a 24-hour period prior to their injury
- Head-injured people who seek help from the state through the Statewide Head Injury Program have generally sustained severe injuries
- Individuals referred to the Statewide Head Injury Program are frequently without any personal financial resources and dependent on public assistance programs
- Individuals with traumatic head injury have serious difficulty becoming employed
- The majority of adults who are head-injured live at home with their families
- The greatest gap in services for people with head injuries is in the area of community reintegration services, e.g., supervised housing, vocational training programs, day services, family support services and recreation/leisure programs



## PREVENTION

Traumatic head injuries often result from motor vehicle-related crashes, falls, sport-related incidents and assaults. Prevention strategies exist that are known to be effective. Massachusetts must take active measures to respond to this problem and begin to reduce the risk of injury for all of its citizens. The state cannot address the needs of people with head injuries and their families without continuing its efforts in the area of prevention.

## SUMMARY

The Statewide Head Injury Program (SHIP) is a national model of state supported services for people with traumatic brain injuries. Since its inception in July, 1985 SHIP has:

- 1 - Provided case management to over 120 people and will increase this number to 180 before the end of this fiscal year
- 2 - Purchased needed 24-hour rehabilitation services for an average of 32 people each year
- 3 - Provided diagnostic and short-term in-patient psychiatric hospitalization services for eligible SHIP clients with no other financial resources
- 4 - Developed community-based residential and day programs that serve up to 54 individuals
- 5 - Provided technical assistance and consultation to a large number of private providers and state agency staff such as D.M.H., D.M.R., D.P.W., D.P.H., O.F.C., MRC/VR and D.O.C.
- 6 - And is planning for the development of at least 4 more programs that will serve an additional 60 eligible clients

Prior to the existence of SHIP there was no central point of coordination and service delivery for people with head injuries within the Commonwealth. SHIP's mandate is to begin to address the gaps in service that exist for this population by creatively utilizing the resources available through the private and public sector. These efforts are just a beginning in the development of a comprehensive service delivery system that can meet the diverse needs of this population. However, there remains a number of need areas that continue to require our attention.

The information presented in this report provides the groundwork necessary for the state to develop short and long-term strategies that will have a positive impact on the present level of care and future quality of life of all Massachusetts residents with acquired brain damage.

# Introduction





## INTRODUCTION

DEBRA S. KAMEN, M.S.  
Director  
Statewide Head Injury Program



## INTRODUCTION

### OVERVIEW

The Statewide Head Injury Program (SHIP), administered by the Massachusetts Rehabilitation Commission's Independent Living Division is submitting this comprehensive report in response to a legislative mandate to identify the incidence of traumatic brain injury (TBI) in the Commonwealth and the program development needs of this population. SHIP has been working in collaboration with a number of other state agencies and facilities in order to produce a carefully investigated and well-documented report. The Center for Survey Research/University of Massachusetts, the Statewide Comprehensive Injury Prevention Program/Department of Public Health, and the University of Massachusetts Medical Center have all played a critical role in the production of THE STATUS OF PEOPLE WITH BRAIN INJURIES In MASSACHUSETTS: EPIDEMIOLOGICAL ASPECTS AND SERVICE NEEDS.

### ORGANIZATION OF THE REPORT

In order to understand the magnitude of the problem that faces survivors of traumatic brain injuries and their families, it is necessary to have some basic knowledge of traumatic brain injury as a disability. Therefore, Chapter I provides the reader with information on the causes of traumatic brain injury in adults and children; national data on the incidence of such injuries and the sub-groups most frequently affected (i.e., sex, age group); and most importantly, the clinical consequences of brain injury. Prognostic indicators used to assess the severity of the injury and an individual's ability to regain functioning are also discussed. The national trends identifying the causes and incidence of TBI are compared to Massachusetts data derived from the Uniform Hospital Discharge Data Set (UHDDS), for the three year period, 1984-1986, obtained from the Massachusetts Rate Setting Commission.

Chapter II of this report outlines the three main stages of recovery - acute care, rehabilitation and community reintegration. Also discussed are the types of programs and/or services within a continuum of care that need to be available to the head-injured people during their recovery process; the clinical components of service delivery

within each model; the primary treatment goals for those participating in these services; and, the estimated fiscal resources necessary to provide these services based on charge data rather than the preferred cost data which is not readily available. It is important to note that this is the first effort made in Massachusetts to identify the continuum of care for this population in the post-acute phase and that the majority of these programs do not presently exist. The Statewide Head Injury Program has made program development a top priority and expects that over the next several years there will be a more accurate means of identifying these related costs based on the actual development and operation of services specific to the unique needs of this population.

The purpose of this report is to present information on the needs of people with traumatic head injuries survivors and their families residing in the Commonwealth. To this end SHIP entered into a cooperative effort with the Center for Survey Research, University of Massachusetts at Boston. A survey was developed and distributed statewide to head-injured people, family members and clinicians. The results of this survey are delineated in Chapter III of this document.

SHIP has been working closely with the Statewide Comprehensive Injury Prevention Program (SCIPP) at the Department of Public Health. Each year almost 8,000 people with traumatic head injuries are discharged from Massachusetts hospitals and the leading causes are motor vehicle-related crashes and falls. We cannot speak of providing services to this population without discussing measures that can be taken to help reduce the risk of such injuries to the residents of this state. Chapter IV will address in detail prevention strategies that should be explored to combat this "Silent Epidemic" as it is referred to by the National Head Injury Foundation.

SHIP has been in existence for over two years. Individuals eligible for services must have survived an externally-caused traumatic brain injury. There have been numerous occasions when people with other forms of acquired brain damage have been determined ineligible because they do not meet this criterion. The diagnosis of brain damage takes many forms. Massachusetts has taken a first step in addressing the needs of a large number of traumatically brain injured people through the development of SHIP, a national model. This research project acknowledges that an even greater number of people with equally significant needs, i.e., those with non-traumatic brain injury, present problems that need to be addressed as well. Therefore, Chapter V of this report will identify non-traumatic brain injuries, their estimated incidence, clinical consequences, prognoses and associated service needs.

Chapter VI of this document will summarize the major findings and outline short and long-term interventions that can be targeted to help residents of Massachusetts whose brain damage interferes with their ability to function independently and has led to the need for life-long services.

#### LIMITATIONS OF THE REPORT

In an effort to describe the magnitude of the problem, data from Massachusetts hospitals were analyzed. These data must be qualified, however, as only those individuals who sustained traumatic brain injuries necessitating hospitalization are included. The annual discharges reported through the UHDDS underestimate the actual number of residents of the Commonwealth who have had a traumatic brain injury and may be in need of services to remediate the consequences of this trauma.

When the needs assessment project was initiated it was hoped that the sample group selected would be representative of the head-injured population statewide. However, due to incomplete data derived from the UHDDS precise comparisons between the sample group and the total population of head-injured people could not be completed. This limited our ability to make recommendations regarding the service needs of the total population. In addition, the reader should understand that even when severity of injury is measured by such things as loss of consciousness this indicator does not always predict the complexity of service needs.

The limitations with respect to interpretation of the information derived from the UHDDS are also apparent when analyzing discharge data associated with non-traumatic brain injuries.





# Chapter I





TRAUMATIC BRAIN INJURY:  
AN OVERVIEW

FRANCESCA A. LAVECCHIO, PH.D.  
Chief Neuropsychology Consultant  
Statewide Head Injury Program



" Two facts - head injury does not change the life expectancy and the right that the head injured have a quality to their lives. "

- Family Member

" Life is never the same after the injury. "

- Person with a head injury

"... All head injuries can have their long-term effect on family and friends as well as (the) victim. "

- Family Member



## DEFINITION

Traumatic encephalopathy refers to brain damage that results from an external (mechanical) force. There are two basic categories of traumatic brain injury (TBI):

Closed Head Injury (CHI) which typically results from blunt trauma to the head (e.g., head to windshield).

Penetrating Head Injury, which refers to a traumatic head injury which results from a missile-like object (e.g., bullet).

## EPIDEMIOLOGY (NATIONAL)

Prior to 1974, the majority of epidemiological studies of traumatic brain injury were completed in selected populations or countries other than the United States (1). In 1975, information derived from the HDS (Hospital Discharge Survey), which excludes VA and military hospitals, revealed that there were 35,300 patients discharged with a diagnosis of head injury, equivalent to a rate of 170/100,000. These figures exclude those with mild head injury and those individuals who died at the scene of the accident (2).

In 1974, the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) initiated a program of large-scale surveys, in an effort to estimate the incidence, prevalence, mortality, and morbidity of various diseases, utilizing the methodology of probability sampling. The National Head and Spinal Cord Injury Survey (HSCI Survey) represents one of the surveys commissioned by NINCDS to determine the scope of traumatic head injury in the United States (excluding Alaska and Hawaii). The survey population consisted of persons who received in-patient care in United States hospitals from 1970 to 1974.

This study estimated the occurrence of head injury to be 422,000/year or a rate of occurrence of 200/100,000 population. The study also revealed that head injury occurs most often in the 15 to 24-year old age group and more often in males than in females. The incidence rate for males was calculated to be 272/100,000, while for females it was 132/100,000. Motor vehicle accidents constitute the most common cause (49%) while falls were the second most common cause (28%) and more likely to occur in those under age 15 and the elderly.

Head injuries were found to occur most often in September and April and most frequently on Fridays, Saturdays, and Sundays. With respect to lengths of stay (LOS's), 55% were admitted for three days or less, while 20% had lengths of stay of 5-9 days, and 10%, 20 or more days. Male patients in the 15-24 year old age group and those who sustained their head injuries secondary to a motor vehicle accident (MVA) experienced the longest lengths of stay. Direct care costs for head injured survivors were estimated to be \$2.4 billion in 1974. The mortality rate for admitted patients was 3%; however, it should be emphasized that those who died at the scene of the accident and those who were determined to be dead on arrival were not included in the study. Also, patients who sustained mild head injuries and were not admitted to the hospital were also excluded from study statistics (3-6).

In many respects, it is difficult to compare other epidemiological studies to the one described above, or with each other, as inconsistent criteria for determining inclusion or exclusion of cases (e.g., ICD codes) have been employed. In general, however, the findings of the National Head and Spinal Cord Injury Survey have been substantiated by other studies of defined populations. These are summarized in TABLE 1.1 (7-15). Notable exceptions are the findings of studies completed by Whitman, et. al. (16) and Dasai, et. al. (8) which reveal interpersonal injury/assault, versus motor vehicle accidents, to be the primary cause of head injury in inner city Blacks, who also exhibit a significantly greater occurrence rate, when compared to capitatize Caucasians in suburban and rural communities.



TABLE 1.1

REFERENCE	POPULATION STUDIED	AGE GROUP WITH HIGHEST FREQUENCY	CAUSES			INCIDENCE	MORTALITY (RATE OR PERCENT)
			MVA	FALLS	ASSAULT/ INTERPERSONAL INJURY		
Annegers, et. al., 1980	Olmstead County, Minnesota	15-24 years	37%	29%	3.8%	270/100,000 (M)	32/100,000 (M)
Klauber, et. al., 1981	San Diego County, CA	10-29 years	53	30	11	116/100,000 (F)	9/100,000 (F)
Desai, 1983	Cook County Hospital	Adults (Non-White) Children (Non-White)	22.4 14.4	15.2 45.8	56 22	Not Reported	2.4%*
Gale et. al., 1983	Seattle, Washington	15-24 years	38.4	20	17	Not Reported	19%*
Fife & Jagger, 1984	University of Virginia Hospital	Median = 23 years	56	19	10	Not Reported	3%*
Kraus, 1984	San Diego, CA		48	21	12	180/100,000	17%
Jagger, et. al., 1984	North Central Virginia	15-19 years	55	20	11	208/100,000	6.5%
Whitman, et. al., 1984	Chicago and Evanston, IL	20-40 yrs., Inner City Blacks	31	20	40	403/100,000	32/100,000
		0-44 yrs., Evanston Blacks	32	21	26	394/100,000	19/100,000
		0-20 yrs., Evanston Whites	39	31	10	196/100,000	11/100,000
Fife, et. al., 1986	State of Rhode Island	15-19 years	39	35	9	152/100,000	8%*

\* Indicates that cases where the individual died at the scene of the trauma, or when the individual was dead on admission, were excluded in calculating mortality rates or incidence

\* Indicates that cases where the individual died at the scene of the trauma, or when the individual was dead on admission, were excluded in calculating mortality rates or incidence

### EPIDEMIOLOGY (PEDIATRIC POPULATION)

Injuries represent the leading cause of mortality and morbidity in children after the first year of life. Approximately 50% of all deaths in children, ages 1-14 years, are due to injury, and 43% of all deaths in children, ages 5-9 years, are attributed to head injury (18, 19). The most common cause of head injury in children is falls. Motor vehicle accidents constitute the second leading cause; however, in the majority of cases, the child is a pedestrian, occupant of a motor vehicle, or involved in a bicycle-auto/ truck collision (17, 20, 21). Agran, et. al. have noted that in 23% of pediatric cases which present at the emergency room, injuries have been precipitated by non-crash events (e.g., sudden stops, swerves, turns, etc.) and an unrestrained child (22). In non-motor vehicle cases in children under the age of seven years, head injury has occurred as the result of falls involving home furnishings, fixtures, and structures (e.g., stairs). In infants, falls from cribs, high chairs, and baby carriages have been implicated, while in older children, head injuries have been associated with recreational activities and utilization of sports equipment (23). Paralleling the adult population, childhood head trauma occurs more frequently in boys than in girls. In a study completed by Kraus, et. al. in 1986, where the overall incidence of head trauma in children was found to be 185/100,000, the rate for boys was 235/100,000, while the rate for girls was 132/100,000 (20).

In 1984, 1,727,000 children in the United States were reported to be abused or neglected. In Massachusetts, 49,799 cases of child abuse/neglect were reported in 1986 (24). Although comprehensive epidemiological and follow-up studies have not been completed to date, child abuse has been considered a not uncommon cause of head injury. In 1974, Caffey described the Whiplash Shaken Infant Syndrome, which results in traumatic brain injury secondary to the grabbing and shaking of infants by their extremities or by the thorax. This form of child abuse precipitates the whiplashing of the head onto the thorax and associated bilateral hematomas and intraocular hemorrhages, in the absence of external signs of trauma to the head and neck (25).

### EPIDEMIOLOGY (OTHER)

The epidemiology of traumatic head injury, in both adults and children, has also been studied in a variety of sub-populations. For example, Kraus and Fife have studied the incidence and causes of work-related brain injuries in males in San Diego County. An overall annual incidence rate of work-related brain injuries was found to be 19.8/100,000 workers. For military workers, however, the rate was 37/100,000, while the rate for civilian workers was 15.2/100,000.



Fifty-four percent of head injuries among civilians resulted from falls, while 57% of brain injuries sustained by military workers were associated with off-road operation of motor vehicles (26).

The most common sports associated with head injury include horseback riding, football, sledding, baseball and softball, and ice hockey (7, 27, 28). A dementing disorder of the Alzheimer's type, known as dementia pugilistica, has been observed in both professional and amateur boxers who have sustained multiple blows to the head (29, 30, 31). Head injury has also been found to be associated with alcoholism in two respects: (a) alcoholics with a positive family history of alcoholism are more likely to exhibit a history of head trauma (32); and (b) alcohol intoxication is often a concomitant finding in patients who are hospitalized for head injury (33, 34, 35).

Approximately 30,000 people in the United States die of suicide each year. Both attempts and completed suicides are associated with depression, and it is estimated that 10 to 14 million persons are moderately or severely depressed. Another not uncommon cause of mortality and morbidity, particularly among males, which is associated with head trauma results from completed suicides and suicide attempts by jumping or firearms (36, 37). Penetrating head injuries are also more commonly observed among war veterans (38).

#### EPIDEMIOLOGY (COMMONWEALTH OF MASSACHUSETTS)

The incidence of traumatic head injury cases in the Commonwealth of Massachusetts has been estimated from data derived from the Uniform Hospital Discharge Data Set over a three year period. Between the years 1984 and 1986, a total of 23,954 individuals were discharged alive from Massachusetts hospitals with either a primary or secondary diagnosis of traumatic brain injury (TBI). There was a 3.9% death rate across the three years studied. A breakdown of cases, by age and year, is detailed in TABLE 1.2a while the average frequencies by age over the three years is presented in TABLE 1.2b.

These figures exclude all cases who may have expired prior to or upon arrival at the hospital; those who were only evaluated and/or treated in the emergency room and not admitted; and non-Massachusetts residents. Transfer cases were counted only once.

TABLE 1.2a

TBI: Frequency of Live Discharges  
by Age and Years (UHDDS)

<u>Age (Years)</u>	<u>Total Year</u>			<u>Total</u>	<u>(%)</u>
	<u>1984</u>	<u>1985</u>	<u>1986</u>		
0-2	464	438	436	1,338	(5.6)
3-5	315	277	267	859	(3.5)
6-18	2,247	2,233	2,113	6,593	(27.5)
19-21	718	783	686	2,187	(9.1)
22-29	1,254	1,152	1,225	3,631	(15.2)
30-39	801	857	803	2,461	(10.4)
40-49	501	436	427	1,364	(5.7)
50-59	419	387	377	1,183	(4.9)
60-69	417	443	411	1,271	(5.3)
70-79	529	460	507	1,496	(6.3)
80-89	408	406	443	1,257	(5.2)
90+	88	91	135	314	(1.3)
TOTAL (All Ages)	8,161	7,963	7,830	23,954	(100%)

Over the three-year period investigated, 27.5% of head injuries occurred in school age children (6-18 years old) and an additional 9.1% of head injuries were sustained by children of pre-school age (0-5 years old).

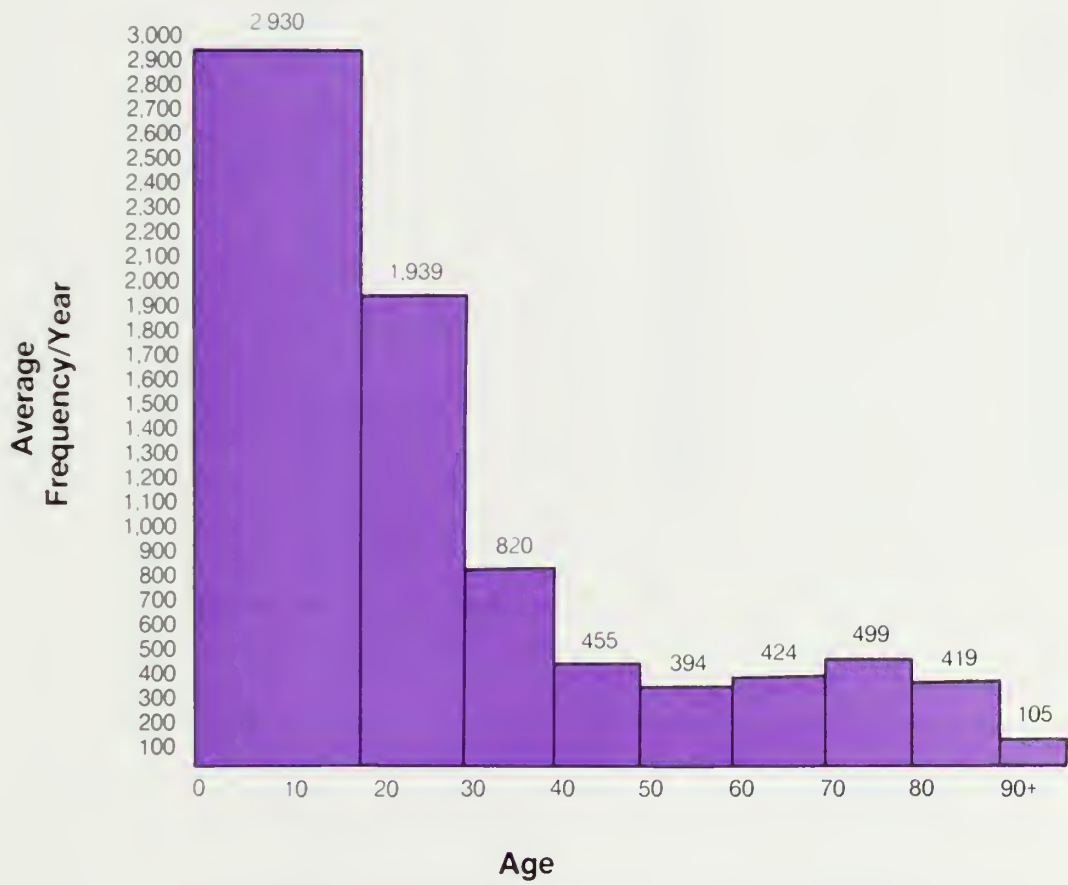
With respect to sex differences, males exhibit a higher frequency for all three years, accounting for 15,001 cases, while, in comparison, 8,946 females were admitted for treatment of TBI (See TABLE 1.3).

In TABLE 1.4, the relative frequencies for the diagnoses selected for study are summarized. The diagnoses listed are in reference to the International Classification of Diseases, 9th Edition, Volume I (ICD-9-CM) (39).

---

**TABLE 1.2b**  
**Average Frequencies (TBI) By Age**

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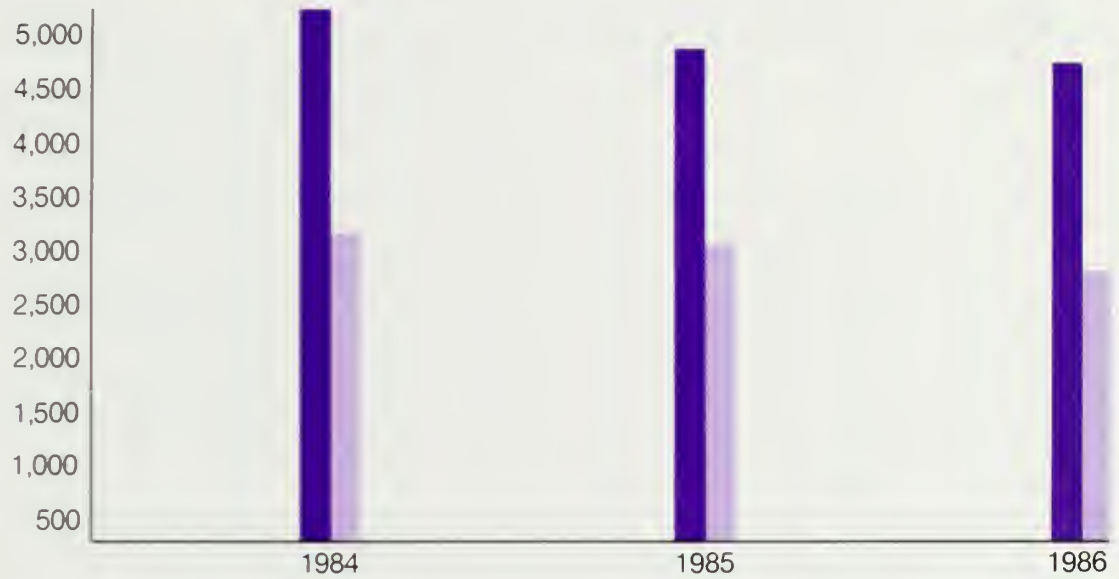
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**TABLE 1.3**  
**Male:Female Comparisons**

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	Males	Females	
1984	5,139	3,021	<div style="display: inline-block; width: 15px; height: 15px; background-color: #000080; border: 1px solid black; margin-right: 5px;"></div> Male
1985	4,950	3,007	
1986	4,912	2,918	<div style="display: inline-block; width: 15px; height: 15px; background-color: #ADD8E6; border: 1px solid black; margin-right: 5px;"></div> Female





TABLE 1.4

Traumatic Brain Injuries  
Epidemiology: Massachusetts UHDDS

<u>Diagnosis</u> (ICD Codes)	<u>Frequencies</u>		
	1984	1985	1986
Fracture of the Skull (Vault) (Codes 800-800.9)	370	373	380
Fracture of Skull (Base) (Code 801-801.9)	508	490	533
Skull Fractures (Other) (Codes 803-803.9)	83	66	74
Fracture (Skull/Face) (Codes 804-804.9)	51	56	46
*Concussion (Codes 850-850.9)	4,779	4,730	4,403
Cerebral Laceration (Codes 851-851.9)	360	358	418
Subarachnoid, Subdural, Extradural (Codes 852-852.5)	334	325	344
Other Intracranial Hemorrhage following Injury (Codes 853-853.1)	100	113	122
Unspecified Intracranial Injury (Codes 854-854.1)	<u>1,576</u>	<u>1,452</u>	<u>1,510</u>
TOTAL (all diagnoses)	8,161	7,963	7,830

\* Concussion: All cases of TBI which were not associated with a fracture or vascular problem (e.g., subdural) are coded as a concussion. Although commonly thought of as a minor head injury, concussions, as specified by ICD codes, include severe TBI.



As an index of severity, the period of unconsciousness was derived for those cases where it was specified (N=12,698). These data are summarized in TABLE 1.5 below:

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TABLE 1.5			
Loss of Consciousness (LOC)*			
	<u>1984</u>	<u>1985</u>	<u>1986</u>
No Loss	1,760	1,998	2,261
< 1 hour	1,713	2,167	2,183
1-24 hours	70	91	115
> 24 hours with return	40	55	65
> 24 hours with no return	54	59	67
LOC, (duration unspecified)	999	961	889
Concussion (Unspecified)	2,154	1,558	1,137
Unspecified	1,331	1,069	1,113

---

\* In 47% of cases, the occurrence or duration of coma was not specified making it difficult to draw conclusions about the severity of injuries sustained by the total discharged population.

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In general, Massachusetts data are consistent with national trends. That is, (a) the majority of cases occur in the pediatric and young adult populations; (b) traumatic brain injuries are more likely to be sustained by males than females; and (c) only a small percentage of individuals who sustain traumatic head injuries die during their hospitalization.

## SEQUELAE

### Moderate/Severe Traumatic Brain Injury

The immediate (acute) sequelae or consequences of moderate/severe brain injuries represent the direct and cumulative effects of contusion (bruising), shearing and laceration of brain structures. Secondary effects include edema (swelling) and the associated compression of the brain. Compression of the brain stem, in particular, leads to impairment of consciousness, which is the most common acute effect of a traumatic brain injury. The Glasgow Coma Scale (See TABLE 1.6) has been used to assess the level of consciousness and the severity of brain injury (40). Patients are evaluated with respect to three variables: eye opening, motor response, and verbal response. Scores vary from 3 to 15. A score of 8 or less is generally considered to be indicative of a severe head injury, while patients who are given scores of 9-12 are considered to have sustained moderate head injuries.

TABLE 1.6

## Glasgow Coma Scale

	<u>Response</u>	<u>Score</u>
Eye Opening	Opens eyes spontaneously	4
	Opens eyes in response to voice	3
	Opens eyes in response to pain	2
	Does not open eyes	1
Motor Response	Follows simple commands	6
	Pulls examiner's hand away in response to pain	5
	Pulls body part away in response to pain	4
	Flexes body in response to pain (decorticate)	3
	Body is extended rigidly in response to pain (decerebrate)	2
	No response to pain	1
Verbal Response	Oriented	5
	Confused and disoriented	4
	Inappropriate vocalization	3
	Incomprehensible sounds	2
	No verbal response	1

Total Score = Eye + Motor + Verbal Scores (EMV)

Disruption of the brain's blood supply may also occur, resulting in ischemia (deficient blood perfusion) and anoxia (lack of oxygen). In some cases, the development of a blood clot, or hematoma, may occur, contribute to compressive effects, and necessitate neurosurgical intervention. Other medical complications, which may need to be addressed in the acute stage of treatment or in later stages of recovery include the following:

- Fractures (skull, extremities, ribs, pelvis)

- Obstruction of the airway or difficulty breathing, which may necessitate the surgical construction of an artificial airway (tracheostomy) and/or mechanically supported respiration (ventilator)
- Seizures (post-traumatic epilepsy)
- Infection of the brain (brain abscess, encephalitis) or brain coverings (meningitis)
- Disruption in the flow of cerebrospinal fluid (fluid surrounding the brain and spinal cord), resulting in hydrocephalus (41).

With respect to the long-term residual effects, survivors of traumatic brain injury exhibit a wide range of handicapping conditions. The most common motor impairments include difficulties with coordination and movement, as well as paralysis, which is typically one-sided (hemiparesis). Sensory impairments include incoordination of eye movement, cortical blindness, and hearing impairments. Patients also exhibit persistent pain syndromes. These sensorimotor impairments, in turn, compromise the head injured individual's ability to perform self-care skills, to access community services, or live independently (42).

In both adults and children, the significance of the behavioral and cognitive sequelae, however, often outweigh physical disabilities and can occur in the absence of physical impairments (43-69). The most common residual deficits in these functional areas are summarized in TABLE 1.7.

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**TABLE 1.7**  
**Cognitive and Neurobehavioral Consequences of TBI**

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<b>FUNCTION</b>	<b>IMPAIRMENTS</b>
<b>Attention/Activity Level</b>	<ul style="list-style-type: none"> <li>Difficulty sustaining attention/concentration</li> <li>Distractibility</li> <li>Difficulty initiating purposeful activity</li> <li>Hypoactivity and lethargy</li> <li>Easy fatigability</li> <li>Slowness of response</li> <li>Hyperactivity and euphoria</li> </ul>
<b>Language</b>	<ul style="list-style-type: none"> <li>Difficulty with production of speech (articulation problems)</li> <li>Difficulties with the expression and comprehension of language (aphasia)</li> <li>Word-finding or naming problems</li> <li>Difficulty with language-related functions (e.g., reading, spelling, etc.)</li> <li>Impaired verbal fluency</li> <li>Loss of ability to communicate verbally</li> </ul>
<b>Memory</b>	<ul style="list-style-type: none"> <li>Disorientation</li> <li>Retrograde Amnesia</li> <li>Anterograde Amnesia</li> <li>Difficulty with acquisition of new information (new learning)</li> </ul> <div style="text-align: right; margin-right: 20px;">         Acute stage       </div>
<b>Executive Functions</b>	<ul style="list-style-type: none"> <li>Difficulty with problem-solving, and development of cognitive strategies</li> <li>Difficulty with development and execution of plans</li> <li>Problems with exercising good judgement and reasoning</li> <li>Problems with organization and prioritizing</li> <li>Difficulty with regulating behavior</li> </ul>
<b>Behavior</b>	<ul style="list-style-type: none"> <li>Personality change</li> <li>Impulsivity</li> <li>Impaired social skills</li> <li>Anxiety</li> <li>Difficulty with recognizing or anticipating the consequences of one's own behavior; egocentrism</li> <li>Inappropriate sexual behavior or loss of interest in sexual activity</li> <li>Aggressive behavior towards others and/or property</li> <li>Self-injurious behavior</li> <li>Emotional lability</li> <li>Depression</li> <li>Limited insight regarding disabilities and behavioral problems</li> </ul>

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It is these impairments which, more than physical handicaps, most often affect the level of functional outcome among head injury survivors. In particular, it is these deficits which prevent, or at least impede, the process of educational and vocational rehabilitation, community reintegration, and the ability of these individuals to achieve independence.

### Minor (Mild) Head Injury

The term concussion refers to a mild head injury, which is associated with brief or no loss of consciousness, or no loss of consciousness. A concussion can occur secondary to a mild blow to the head or through a whiplash injury. The most common symptoms reported by individuals who sustain concussions are summarized in TABLE 1.8 below.

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TABLE 1.8

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#### Symptoms of Postconcussive Syndrome

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Memory Deficits

Attention/Concentration deficits

Irritability

Dizziness

Headache

Sleep disturbance

Easy fatigability

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The persistence of these symptoms may lead to secondary problems of depression, anxiety, and inability to perform at work or school.

### PROGNOSIS

The prognosis for survivors of traumatic head injury is dependent upon a variety of factors, including (a) age at time of injury; (b) severity and nature of medical complications; (c) severity of sensory impairments; (d) severity of communication deficits; (e) the timeliness, adequacy, and appropriateness of acute care and rehabilitative therapies. The depth and duration of coma are generally viewed as the best predictors of survival and morbidity. A persistent Glasgow Coma Scale score of eight or less has been demonstrated to be inversely related to mortality, and the probability that survivors will exhibit severe disability. Head-injured people with depressed Glasgow scores are more likely to remain in a prolonged coma or persistent vegetative state (PVS), as well. An individual in a persistent vegetative state exhibits a sleep-wake cycle, but is unable to make any meaningful contact with his/her environment or exhibit any conscious intelligence (72). PVS patients are entirely dependent for all self-care and require placement in a skilled nursing/long-term care facility. Approximately 1-7% of head injured patients remain in a persistent vegetative state (73).

The length of post-traumatic amnesia (PTA), which refers to the time between the injury and the recovery of continuous memory, has also been used as an index of severity of injury (See TABLE 1.9 below).

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TABLE 1.9

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Post-Traumatic Amnesia

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<u>Length of PTA</u>	<u>Level of Severity</u>
< 1 hour	Mild
1-24 hours	Moderate
1-7 days	Severe
> 7 days	Very Severe

---



The Glasgow Outcome Scale (75) has been used to classify people with head injuries with respect to their level of dependence/independence and social reintegration. The scale (TABLE 1.10) specifies four possible recovery outcomes.

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TABLE 1.10

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Glasgow Outcome Scale

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<u>Level</u>	<u>Functional Abilities</u>
Persistent Vegetative State (PVS)	Totally dependent in all ADL Cannot communicate
Severe Disability (SD)	Requires assistance in ADL Can communicate Very significant neuropsychological deficits and behavioral dysfunction
Moderate Disability (MD)	Independent in ADL Significant neuropsychological deficits and behavioral dysfunction
Good Recovery (GR)	Independent in ADL Intelligence in the normal range Only mild behavioral impairments

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While the prognostic indices and measures described above have been employed by clinicians working in the field of head injury treatment and rehabilitation, their applicability, with respect to assessing the multidimensional disabilities and needs of head injury survivors remains limited. In the subsequent chapters, a detailed description of the recovery pathway, service needs, and service costs associated with each stage of recovery are reviewed. Finally, the results of a comprehensive Needs Assessment (Massachusetts residents), completed by the Statewide Head Injury Program (SHIP) in cooperation with the Center for Survey Research, are presented.

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## Chapter II



STAGES OF RECOVERY: CLIENT PATHWAYS

JULIANNE ZUCK, M. PHIL.  
Consultant  
Statewide Head Injury Program



" It is a long hard lonely road. "

- Person with a head injury

" I want to learn how to take care of myself. "

- Person with a head injury

" The understanding of the pain and personality change, the difficulty we suffer.... They say that we can never be the person we were before this type of accident; that we have to learn to be people we do not choose to be. When we're reaching out for help, please help us. "

- Person with a head injury





## INTRODUCTION

Individuals who sustain a traumatic head injury require a full continuum of services from the moment of injury to the point where they have achieved their maximum level of functioning. In many cases, final resolution of the recovery process leaves them with residual impairment and will require some level of lifetime supervision, assistance, and support.

The full continuum of care for head injury has not yet been specified. While a good deal is known about the emergency and acute medical management of the head-injured, little documentation exists regarding management of the post-acute stages of recovery and virtually no attention has been paid to lifetime services. Dr. Paul Thomas, Director, Medical Sciences Programs, National Institute on Disability and Rehabilitation Research, has stated that "in the later stages of recovery, we move into a gray area that is not well planned and organized. There is to date no consensus on the appropriate service configuration."\*

Long-term rehabilitation and care for the head-injured have emerged as a challenge to the professional community only in the past ten years, and has gained momentum as a public policy issue only in the past five years. First, advances in medical technology are increasing the rate of survival from head injury. The numbers of severely impaired persons are growing and are putting an increasing pressure on the health care system. Second, it had generally been believed that all significant gain would be made within the first six months to twelve months of recovery and that any remaining residual impairment was permanent. The more recent literature has substantiated that the recovery process continues for several years after the initial incident, necessitating the development of more extensive rehabilitative programs (Adamovich, Henderson, and Auerbach, 1985). Third, advocacy efforts on the part of the National Head Injury Foundation which was formed in 1980 brought a visibility to these issues both in the private and the public sectors that had not previously existed. These factors have had a profound impact on head injury survivors, their families, and the health care dollar.

\* Personal Communication

In this document, the continuum of care for the head-injured is outlined based upon the knowledge base that has been developed in the past ten years plus our experience in developing services for other special needs populations. The continuum specified here will not be definitive. A great deal more research and demonstration programs are needed. We can, however, outline the parameters of the system and some working principles of program development based upon certain assumptions about the head injured population that are beginning to emerge in the field.

### THE CLIENT PATHWAY

As was reviewed in Chapter I, the consequences - cognitive, physical, and behavioral - and expected outcomes associated with traumatic brain injury are dependent upon a variety of factors. These include: (a) severity of the injury; (b) development of medical complications; (c) severity of sensory and motor impairments; (d) severity of cognitive and behavioral dysfunction; and (e) adequacy, appropriateness, and timeliness of treatment interventions. It is also important to stress that head injured individuals move through the stages of recovery at varied rates and often in a non-linear fashion, again largely in response to the factors listed above.

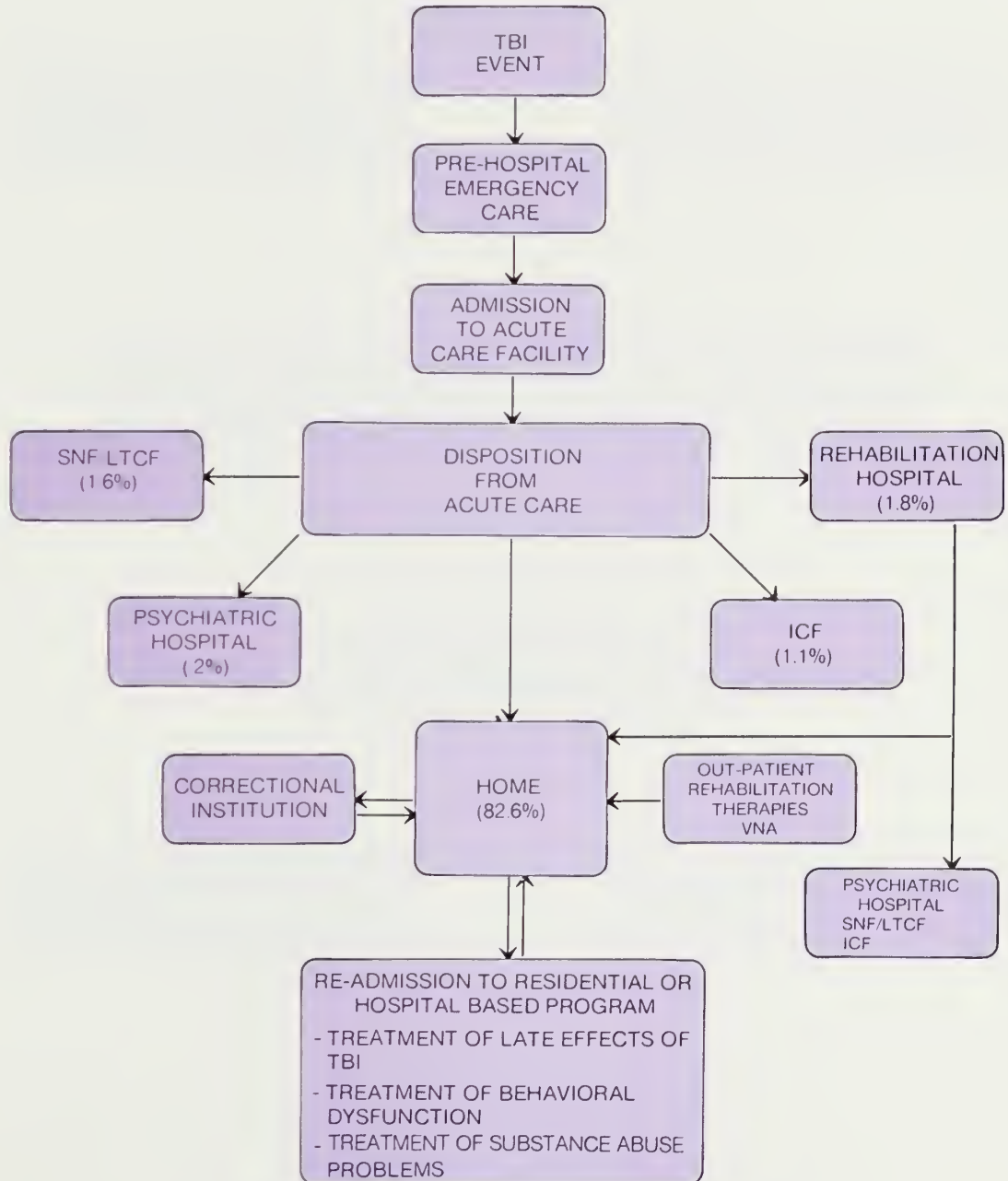
Three broad stages of recovery are generally recognized and will be utilized for discussion purposes in this report:

1. Emergency and Acute Medical Care
2. Rehabilitation
3. Community Reintegration

These pathway components are depicted in Diagrams A and B.



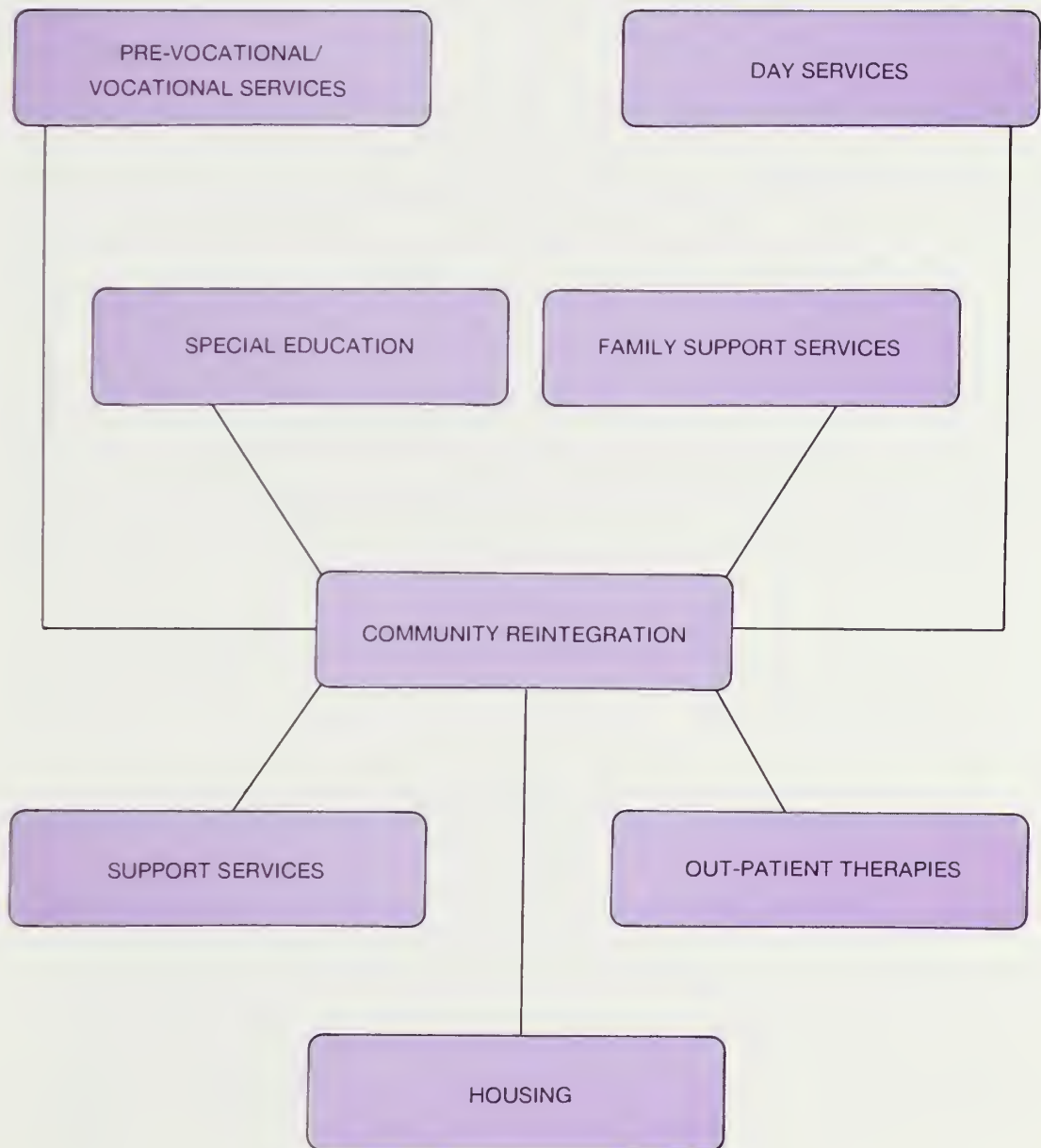
**DIAGRAM A**  
**Continuum of Care**







**DIAGRAM B**





## EMERGENCY (PRE-ADMISSION) AND ACUTE CARE STAGE

### Evolution of Trauma Care

The work of the National Research Council in 1966 on accidental death in the United States brought national attention to the fact that a significant proportion of death and disability is secondary to the initial incident and can be prevented. This study focused national attention on the need to develop emergency medical services systems that would address the factors influencing preventable death and disability.

Through the Emergency Medical Services Systems Development Act of 1973 (PL 93-154), federal funds were made available to sub-state regions to support the development and implementation of regional EMS systems. In 1981, the Omnibus Budget Reconciliation Act consolidated seven HHS categorical programs into the Preventive Health and Health Services (PHHS) block grant, thus allowing states greater discretion in allocating funds and releasing states and regions from stringent federal regulation.

In March 1985, Senators Edward Kennedy and Alan Cranston requested the General Accounting Office to assess the effect of the transition from federal to state leadership under the block grant program. Two of the 18 regions surveyed by the GAO were in Massachusetts. As a result of the GAO's report, Senators Kennedy, Cranston, and Gore filed a bill in January 1987 (S. 10) which incorporates all the recommendations of the GAO report.

### Components of Emergency Medical Services Systems

An Emergency Medical Services System has the following program components:

1. Citizen Access: Emergency medical services are typically initiated by a citizen phone call. The 911 universal access emergency number established in 1968 is by far the most efficient citizen access system. Its advantages are that it is easy to remember, it is known by visitors to the area who will not be familiar with local emergency services, and it automatically routes calls to the appropriate service provider. The efficiency and effectiveness of the citizen access system can be measured by the speed with which the call is made and the ability of the dispatcher to handle the call appropriately. Nationally, almost 50% of the population is covered by 911 access. In Massachusetts, 39% of the population and 21% of the municipalities have 911 access.

2. Emergency Personnel: The ability of on-site personnel to administer appropriate life-saving emergency care is critical to the reduction of death and disability for the seriously injured. There are primarily two levels of pre-hospital care:

Basic Life Support (BLS) - provided by emergency medical technicians trained in noninvasive treatment methods, such as administering cardiopulmonary resuscitation, dressing wounds, and administering oxygen (GAO).

Advanced Life Support (ALS) - a more sophisticated level of treatment delivered by paramedics trained in invasive medical techniques, such as administering drugs intravenously, defibrillating cardiac arrest victims with electric shock, and clearing airways by inserting a breathing tube. Advanced life support is typically given under a physician's direction, whether through radio contact or with written protocols (GAO).

3. Emergency Transportation: Ambulance services may be provided by three types of providers: for-profit companies, not-for-profit companies, and municipal departments. EMTs who staff the ambulances may be paid full-time, paid on-call, or volunteer. EMTs in private companies perform only EMT work. In municipal departments, EMTs may also function as police officers or firefighters, depending upon which department is responsible for ambulance provision. Ambulances must be appropriately equipped to support the level of emergency care provided. For example, ambulances with Advanced Life Support teams must be outfitted with specialized equipment (e.g., defibrillators, intravenous equipment, etc.).
4. Communications: Effective delivery of emergency care requires communication among the service providers involved. Communication systems, in turn, depend upon the sophistication and availability of equipment. The most technologically advanced emergency communications system to date is the C-Med Center, which allows for communication among police, fire, ambulance, and hospitals through a central switchboard. Availability of radio frequencies is also a factor that will influence the effectiveness of the communication network.



5. Trauma Centers: Specialized trauma centers evolved as a programmatic response to the recognized need for timely and specialized intervention for critically injured victims. One of the advantages of a trauma center is that trained emergency personnel and specialty physicians are available immediately. A concentration of severely injured patients allows the team members to become proficient in their individual skills and in the coordination that is essential for rapid response to life-threatening situations. The size of the caseload is important both to justify the cost of maintaining a trauma service and to assure quality care through the experience gained in repetition. The importance of this factor is emphasized in the standards established by the American Congress of Surgeons, which recommend that a physician see 50 patients per year as the basis for skill retention. Thus a Level I trauma center should treat between 600-1000 trauma victims per year, while a Level II center should treat 350-600 cases per year (ACS/1983).

In Massachusetts, each of the six EMS Regions have established protocols regarding triage to the appropriate hospital. In more densely populated areas, the protocol for a seriously injured patient is usually to be taken directly to a trauma center (see TABLE 2.1). In rural areas, patients may be taken to the nearest hospital for stabilization and then transferred to a trauma center if indicated.

TABLE 2.1  
Designated Trauma Centers In Massachusetts

<u>Region</u>	<u>Level</u>	<u>Trauma Center</u>	<u>Town</u>
I. Western Mass.	1	Bay State Medical Ctr.	Springfield
	2	Berkshire Medical Ctr.	Pittsfield
II. Central Mass.	1	Univ. of Mass. Medical Ctr.	Worcester
	*	St. Vincent's Hospital	Worcester
III. Merrimack Valley	2	Lawrence General Hospital	Lawrence
	2	Lowell General Hospital	Lowell
IV. Metropolitan Boston	1	Boston Emergency Medical Ctr. New England Medical Ctr. Boston City Hospital University Hospital	Boston
	1	Longwood Area Trauma Ctr. Beth Israel Hospital Brigham and Women's Hosp. Children's Hospital	Boston
	1	Mass. General Hospital Trauma Center	Boston
V. Southeastern Mass.	None		
VI. North Shore	2	Atlanticare Medical Ctr. (Lynn Hospital)	Lynn

\*Neuro-spinal trauma center only

N.B.: Several additional acute care hospitals have met the criteria for Level 1 or 2 trauma care but have not received official designation from their EMS Regional Council.

Source: Emergency Medical Resources in Massachusetts, Massachusetts Department of Public Health, January 1986.

### Goals of Service Delivery (Acute Stage)

The primary goals of treatment in this stage are two-fold: 1) to ensure the survival of the patient by stabilizing vital functioning (e.g., respiratory, cardiac, metabolic functions); and 2) to prevent, reverse, or halt the secondary processes or complications associated with traumatic brain injury (e.g., brain edema, hematoma, etc.).

The research literature has demonstrated that timely and aggressive diagnosis and treatment during this stage is critical with respect to reducing mortality and morbidity. Cowley (1973) reports on statistics that indicate that the mortality rate for trauma victims increased three-fold for every 30-minute lapse without care. Cales (1984) found a bimodal distribution for early death secondary to blunt trauma, with peaks ten minutes after injury and again after 60 minutes. His data are consistent with the concept of the so-called "golden hour" coined by Cowley in 1977. In a study of patients with traumatic acute subdural hematoma, Seelig et. al. (1981) reported a 30% mortality rate for those undergoing surgery within four hours of injury versus a 95% mortality rate for surgery conducted after six hours. Lillehei and Hoff (1985) reported that 75% of head injury victims reaching the hospital alive have some reversible injury necessitating aggressive management.

Active "preventive rehabilitation" during the acute care stage has also been emphasized by Perry (1983) and other clinicians. The goals of preventive rehabilitation are to prevent complications (e.g., pressure sores, contractures, muscle atrophy, infection, etc.) associated with prolonged hospitalization and inactivity.

### Costs (Acute Care)

The direct costs of emergency and acute medical care include the response of local police and fire departments, ambulance services, emergency room care, physician fees not included in hospital charges, contracted services (e.g., x-ray), and insurance administration costs, in addition to hospital charges. An estimation of the cost of these services for head injured victims was beyond the scope of this report. However, charges as reported to the Rate Setting Commission for hospitalization services give some indication of the magnitude of the problem.



The Uniform Hospital Discharge Data Set (UHDDS) was utilized to explore trends in hospital-based care for the traumatically head-injured. The population includes all discharges who were Massachusetts residents; it includes the multiple discharges for patients who were transferred from one acute care facility to another, and patients who died during their hospitalization.

Hospital charges are influenced by numerous factors, including pricing decisions made in relation to cost containment in Massachusetts. The data presented in TABLE 2.2 are offered to suggest trends in provision of acute care, rather than precise cost measures. TABLE 2.3 summarizes the list of anticipated payors.

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TABLE 2.2  
Hospital Charges (TBI)\*

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	1984 <u>N = 8819</u>	1985 <u>N = 8689</u>	1986 <u>N = 8503</u>
Total Charges	\$41,519,852	\$45,156,733	\$49,674,526
Average Charge per Discharge	4,708	5,197	5,842
Average Charge for the Highest 10%	30,408	33,099	36,622
Average Charge for the Highest 1%	110,311	111,055	120,066

\* Average charges per discharge are misleading since charge data are not normally distributed. At least 80% of all discharges have charges lower than the average. Cases in the lowest tenth percentile account for less than 1% of all charges, whereas cases in the highest tenth percentile account for almost two-thirds of all hospital charges. This trend is consistent in all three years.

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TABLE 2.3  
Anticipated Payor (Acute Care)

Payor	Year			Total	% of Three-Year Total
	1984	1985	1986		
Blue Cross	2,352	2,221	2,054	6,627	25.5%
Commercial	1,828	1,660	1,558	5,046	19.4
HMO	200	393	444	1,037	4.0
Workers Comp.	292	306	288	886	3.4
Medicare	1,368	1,322	1,428	4,118	15.8
Medicaid	871	786	790	2,447	9.4
Other Gov't	40	28	54	122	.5
Self-Pay	1,631	1,717	1,589	4,937	19.0
Free Care	106	102	88	296	1.1
Unknown	131	154	210	495	1.9
	8,819	8,689	8,503	26,011	100.0%

Trends in length of stay are similar to those for charge data. Thirty percent of the population have overnight stays only. Almost 80% of the population have lengths of stay less than the average. On the other hand, the highest tenth percentile of cases accounts for almost 60% of all bed days. TABLE 2.4 displays this information.

TABLE 2.4  
Length Of Stay (Acute Care)

	1984 N = 8819	1985 N = 8689	1986 N = 8503
ALOS All Cases	7.0	7.3	7.2
ALOS Highest 10%	41	43	43
ALOS Highest 1%	128	143	131

Those discharged patients who were transferred to a rehabilitation hospital had the highest average charges and the longest lengths of stay (\$33,828 and 42 days per patient averaged over a three-year period). Those patients discharged to home without home health care arrangements had the lowest average charges and shortest lengths of stay (\$3,097 and 4.6 days per patient averaged over a three-year period). The information regarding disposition obtained from the UHDDS does not indicate, however, how many patients presumably discharged without continued care may have participated in out-patient rehabilitation programs or were later re-admitted to rehabilitation or skilled nursing facilities (see TABLE 2.5).

TABLE 2.5  
Disposition Of TBI Patients Discharged  
From Acute Care

<u>Dispositon</u>	<u>Year</u>			<u>Three-Year Total</u>	<u>% of Total</u>
	<u>1984</u>	<u>1985</u>	<u>1986</u>		
Home	7,394	7,156	6,948	21,498	82.6%
Home with Home Health Care	260	262	271	793	3.0
Acute Care Hospital	255	253	209	717	2.8
Nursing Home	138	120	170	428	1.6
ICF	96	100	91	287	1.1
Rehabilitation Hospital	123	141	202	466	1.8
Psychiatric Hosp.	18	17	14	49	.2
Other	47	104	147	298	1.1
Against Medical Advice	171	165	118	454	1.7
Deceased	<u>317</u>	<u>371</u>	<u>333</u>	<u>1,021</u>	<u>3.9</u>
	8,819	8,689	8,503	26,011	99.8%*

\* Due to rounding error

## REHABILITATION STAGE

### Evolution of Rehabilitation Care

In the past 15 years, as more attention has been focused on the effectiveness of rehabilitation for the head-injured, established rehabilitation settings have needed to expand the medical model in order to adequately address the total range of impairment in head injury. Perry (1983) has noted that "equivalent mental rehabilitation had to await the formulation of effective cognition assessment techniques. Only then could goal-oriented therapeutic programs be formulated." Other authors have noted the importance of additional program components: psychotherapeutic intervention and family involvement. The major conclusion to be drawn from the work to date is that a head injury program must encompass attention to all aspects of the client's functioning - physical, cognitive, and psychosocial:

Physical Rehabilitation: focus on restoration of physical function such as ambulation, hand dexterity, bowel and bladder continence, patient self-care in required medical procedures.

Cognitive Rehabilitation: focus on cognitive functioning such as memory, concentration, orientation, organization, problem-solving, speed of processing, communication.

Psychosocial Rehabilitation: focus on amelioration of behavior difficulties and psychiatric sequelae, psychological reactions and adjustment to disability, interpersonal skills.

The following program models are included in the continuum of care in the rehabilitation stage.

Hospital-Based Head Injury Rehabilitation is, by definition, conducted in a rehabilitation unit of an acute care hospital, a specialty rehabilitation hospital, or a rehabilitation unit of a chronic care hospital.

Nursing Home-Based Rehabilitation occurs in skilled nursing facilities (SNF) or Long-Term Care Facilities (LTCF). Patients may be transferred to these programs directly from an acute care hospital, from a rehabilitation hospital, or from the community. Clients whose rate of recovery is slower or who require extended rehabilitation may be admitted to these programs. These facilities, as well as some DPH hospital units, may also provide specialized coma care and care for patients who continue to require ventilator support or an artificial airway and aggressive respiratory therapy.



Out-Patient Rehabilitation is provided by rehabilitation hospitals, acute care hospital out-patient departments, and to some extent free-standing clinics in the Commonwealth.

Home-Based Rehabilitation is provided by certified Home Health Agencies in Massachusetts. Home-based services may include nursing; physical, occupational, and speech therapies; and home health aides.

In general, these programs represent different levels of medical and therapeutic intervention as well as different levels of cognitive recovery. These programs are designed for moderately and severely injured persons without significant behavioral complications.

#### Goals of Service Delivery (Rehabilitation Stage)

Rehabilitation is defined as those activities geared to restoration of function once a patient is medically stable. More specifically, the goals of rehabilitation are:

1. to enhance and channel recovery of function
2. to prevent secondary complications which will lead to further disability
3. to facilitate the development of compensatory strategies in areas of residual permanent impairment

The Commission on the Accreditation of Rehabilitation Facilities (CARF) has specified guidelines for the development of rehabilitation programs in both rehabilitation hospitals and nursing homes. The CARF standards emphasize the following program components:

1. Interdisciplinary team approach to include occupational, speech and language, physical therapies; neuropsychology; nursing; social services.
2. Appropriate medical consultation/liaison services, including physiatry, neurology, neurosurgery, orthopedics, etc.
3. Ongoing staff training and education.
4. Utilization review and active discharge planning.
5. Case management system.

## 6. Family involvement and support services.

The reader is referred to the CARF Standards Manual for more detailed information.

### Costs (Rehabilitation Stage)

Trends in charges for inpatient rehabilitation care were estimated from data provided by two Massachusetts rehabilitation hospitals. These two facilities admitted a total of 136 head injured patients in 1986. The average length of stay was 50 days. Charge data for these hospital programs are summarized in TABLE 2.6.

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TABLE 2.6  
Hospital-Based Rehabilitation  
Charge Data: 1986

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	<u>#</u> <u>Discharges</u>	<u>ALOS</u>	<u>Average</u> <u>Total</u> <u>Charge/Day</u>	<u>Average</u> <u>Total</u> <u>Charge/</u> <u>Patient</u>	<u>Annual</u> <u>Total</u> <u>Charges</u>
Hospital A	58	50.2	\$549.44	\$27,582	\$1,599,750
Hospital B	78	50.0	551.61	27,580	2,151,279

---

Utilization and charge data from inpatient rehabilitation facilities appear to follow a pattern similar to that of acute care hospitals in that a small number of patients have disproportionately long lengths of stay and high total charges. For example, for one hospital surveyed, those patients who fell in the lower 10% of the distribution with respect to charges and length of stay accounted for 1% of the total charges for the group admitted, whereas, the upper 10% of patients accounted for 35% of the total charges and had the longest lengths of stay.

This skewed distribution is reflected in comparing median and average data. In a study reviewing the application of DRGs to rehabilitation hospitals conducted by the Rand Corporation, the median length of stay for brain injury was 28 days and the median total charge was \$11,413 (Hosek et. al., 1986). Comparable data from one of the Massachusetts hospitals was 34 days and \$19,210. The difference in the two sets of median figures may partly be explained by the fact that the Rand study included non-traumatic head injury diagnoses such as anoxia, infections, and brain tumors.

In general, inpatient hospitalization for rehabilitation is covered by health insurance policies. A breakout of payors for the combined discharged population of the two hospitals surveyed in 1986 is summarized in TABLE 2.7.

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TABLE 2.7  
Payor Distribution: Hospital-Based Rehabilitation

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<u>Payor</u>	<u>N</u>	<u>% of Sample Surveyed</u>
Blue Cross	44	32%
Commercial	38	28
Medicare	18	13
Medicaid	24	18
Workers Comp.	7	5
Other	<u>5</u>	<u>4</u>
	136	100%

---

Brain injury programs provided in nursing home settings in the Commonwealth are primarily available to head injury survivors with private insurance coverage. The cost of these programs vary from \$350/day to more than \$800/day. These programs are, at present, generally inaccessible to Massachusetts Medicaid patients, given the current reimbursement rate, and many patients admitted to these programs are from out-of-state.

Out-patient and home health services are provided on a fee-for-service basis. The amount of service delivered, and therefore the charges, are dependent upon the clients' needs. In many cases, insurance will not cover these services on an extended basis.



### Re-Admissions

During the course of recovery in the post-acute stage, it is sometimes necessary for the traumatically brain-injured client to be readmitted to a hospital or residential treatment facility. The primary precipitating conditions include:

1. Admission to acute care for treatment of the late effects of the head injury (e.g., orthopedic problem); development of a secondary late complication (e.g., infection); or surgical procedures (e.g., cranioplasty).
2. Admission to a psychiatric hospital or neurobehavioral treatment program for evaluation and treatment of secondary neuropsychiatric disorder (e.g., depression associated with suicide attempt) or neurobehavioral decompensation (e.g., onset of assaultive behavior).
3. Admission for treatment of substance abuse (e.g., detox).
4. Admission to a residential (special education) program when a child is unable to be maintained in a community placement, most often because of behavioral problems.

It is noteworthy, particularly with respect to the development of severe neurobehavioral dysfunction, that these clients, both children and adults, have been frequently transferred to facilities outside Massachusetts, since to date, there have been no appropriate treatment programs within the Commonwealth to which these patients could be admitted. Many of those with neuropsychiatric disorder have been inappropriately admitted to state psychiatric facilities and placed with chronically mentally ill patients. In some cases, the head-injured with significant neurobehavioral dysfunction have had to face criminal charges resulting in incarceration.

### Costs

For re-admissions to acute care, costs vary in response to reasons for admission, procedures performed, lengths of stay, and development of secondary complications. The costs associated with neurobehavioral treatment programs range from \$100,000 to \$250,000/year/client.

## COMMUNITY REINTEGRATION STAGE

### Evolution of Community Re-Entry Programs

This portion of the continuum of care is largely in a developmental stage, as the majority of program models delineated below do not currently exist. Based upon the results of the SHIP Needs Assessment (See Chapter III) and collective knowledge concerning the long-term consequences of traumatic head injury, it is anticipated that these programs will need to be developed in order to meet the needs of the head-injured in Massachusetts.

Traditionally, it has been presumed that community re-entry programs should be designed for individuals who have potential for living in community-based settings and working in supported/supervised employment or competitive situations. It has also been presumed that these individuals have completed their formal rehabilitation and now exhibit static, residual impairments, for which compensatory mechanisms have been developed or will need to be developed.

In contrast to this view point, longitudinal studies of the head-injured indicate that subtle functional changes continue to occur over time, many years after head injury. Also, problems (particularly behavioral and psychosocial) that were not evident at the time of discharge from acute care or a rehabilitation facility, may emerge subsequently. Finally, the need for a variety of support services, again either not necessary or not apparent within a hospital setting, becomes more evident when head-injury patients are discharged to the community, most often to the care of their parents or other family members.

### Goals of Service Delivery (Community Reintegration Stage)

The goals of community reintegration strategies include:

1. To strengthen and maintain the physical, cognitive, and behavioral gains made in rehabilitation.
2. To enhance community and social skills and psychosocial functioning.
3. To enhance prevocational and vocational skills and facilitate employment.
4. To provide support services to facilitate community living.
5. To coordinate and ensure appropriate services through case management and advocacy efforts.

6. To provide opportunities for each client to engage in activity that promotes a sense of dignity, self-worth, purpose, and contribution.

Again, based upon the results of the SHIP Needs Assessment, it is anticipated that program development will be needed in the following areas:

Vocational Services - including assessment, counseling, and placement (Supervised Employment/Supported Work).

Day Services - including day treatment/day habilitation and day activity programs.

Family Support Services - including respite care, family counseling, and family training.

Special Education Services - including hospital/home transitional programs, home-based programs, day school programs, and residential schools.

Support Services - including, but not limited to, the following:

- Personal Care Attendants
- Homemaker Chore Programs
- Visiting Nurse
- Leisure/Recreational Programs
- Adaptive Equipment Services
- Environmental Adaptation Services
- Legal Advocacy
- Transportation

Out-Patient Therapies - including rehabilitative, neuropsychiatric, substance abuse.

Housing - including community re-entry/transitional living programs, supervised housing, and cooperative apartments with support staff and services.

While many of the services listed above are provided through state agencies, the delivery of services occurs in a fragmented manner, or existing services have not been tailored to meet the specialized needs of the head-injured.

Costs (Community Reintegration Stage)

Cost data are not currently available for this stage of the continuum and would be expected to vary significantly depending upon each client's needs and the specific components of the program model.



## DEVELOPING A SYSTEM OF CARE FOR PERSONS WITH TRAUMATIC BRAIN INJURY

The goals to be achieved in developing a service delivery system for head injury survivors should be:

1. To minimize the impact of disability and secondary consequences by providing adequate, appropriate, and timely care.
2. To maximize recovery, rehabilitation and integration of the head injured individual.
3. To utilize resources in the most cost effective manner.

Recommended guidelines for development of the system of care are summarized below:

1. Services for the head-injured must be planned, organized, and developed as an integrated system of care.

The development of a system of care must give adequate attention to program components, client linkages, system linkages, and resource generation. Focus on a system of care will help avoid gaps in service, duplication of service, and fragmented service.

2. Services should be comprehensive, coordinated, and continuous over time.

While the notion that a system of care should be comprehensive, coordinated, and continuous was first and most systematically incorporated into public policy in the community-based mental health movement of the early 1960's, the basic principles are equally as relevant for other special needs populations such as the head-injured.

Comprehensive care means that a person's total needs must be addressed at each stage of recovery in order that improvement in one area of functioning is not compromised because of neglect in other areas.

Coordinated care means that all players in the individual treatment plan and service plan at any one point in time coordinate their goals and strategies into one overall consistent plan for the client. This principle is critical in head-injury management given the typical cognitive impairments of impaired memory, difficulty in generalizing learning, reliance on external structuring and cuing.

Continuous care over time implies that the head-injured person and his or her family receive the appropriate services at the time that they need them.

3. Generalist case management services must be the core of a comprehensive service system.

Head injury typically results in a complex and individualized clinical picture of physical, cognitive, emotional, and behavioral impairments as well as medical complications. Many different caregivers, community resources, and funding sources will be involved in the recovery, rehabilitation, and reintegration of the head injured individual. Appropriate and timely identification, mobilization, and coordination of services through an effective case management system is essential in order to meet system goals.

4. Early, appropriate, and timely intervention appears to maximize recovery and reduce long-term costs of care.

The issue of early, appropriate, and timely intervention has been raised at every stage in the recovery process. First, recent research findings suggest that there is an optimal point in physiologic and neurologic recovery when active intervention can maximize successful outcome. If this point is missed, the opportunity is lost or is regained at greatly increased costs. Secondly, lack of appropriate and timely intervention can result in complications which make treatment prolonged, more costly, and may result in increased disability.

In a retrospective study of 36 patients matched for severity and complications of injury, Cope (1982) found that total hospitalization in acute care and rehabilitation combined was 80.2 days more on the average for late admissions to rehabilitation (defined as more than 35 days post-injury) versus early admissions to rehabilitation (less than 35 days post-injury). At a conservative estimate of \$500 per day, this would lead to a savings of \$40,000 per patient in hospitalization costs.

Once the head injured person is discharged from a hospital setting, a lack of continuity of care may lead to a loss of functional gains that have been made and a loss of the considerable investment that has already been made in the client's recovery. Without continued guidance, maladaptive coping strategies may develop, which makes treatment more complicated and costly should programming be resumed. Behavioral patterns such as substance abuse and criminal involvement may also result and create additional burdens on the human service system.

Finally, to the extent that head injured persons can achieve independence in daily activity and return to work, their decreased dependence on public support will be a long-term cost savings to the system.



5. The service system should allow for the development of programs at the community, regional, and state levels in order to utilize specialized manpower most effectively.

Planning for the geographic distribution and system capacity of each program component must take into account the demand for these services and the need for highly specialized and experienced clinicians.

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## Chapter III





AN ANALYSIS OF THE NEEDS OF PEOPLE WITH TRAUMATIC HEAD  
INJURIES: COMMONWEALTH OF MASSACHUSETTS

THOMAS W. MANGIONE, PH.D.  
Senior Research Fellow  
Center for Survey Research  
University of Massachusetts at Boston

DEBORAH POTTER, M.A.  
Senior Research Assistant  
Center for Survey Research  
University of Massachusetts at Boston

DEBRA S. KAMEN, M.S.  
Director  
Statewide Head Injury Program

FRANCESCA A. LaVECCHIO, PH.D.  
Chief Neuropsychology Consultant  
Statewide Head Injury Program



" The effects of head injury are long lasting. The action is insidious, often times marked and/or complicated by substance abuse resorted to to relieve anxiety, depression. "

- Person with a head injury

" I cared for this person almost totally alone during the 7½ years before he was placed in a nursing home. I found virtually no support, services or respite relief during that period. I was isolated and overworked by the demands of this person's condition and the needs of two small children. "

- Family Member

" (I want) to earn a living and live somewhat of a normal life. "

- Person with a head injury

" Help is available but sometimes very difficult to obtain and very difficult to find out about... "

- Family Member

" If you don't have insurance or the money you don't get the help/services you're supposed to get.... "

- Person with a head injury

" Services should be given to all head injured people who have the ability to live outside of a long-term care facility.... "

- Person with a head injury

" xxx is in jail now because the system didn't help. If this young man could have received help long ago this wouldn't have happened. He went without training of any kind, he cried out for help and had a door slammed in his face.... "

- Family Member

" My husband and I were to retire in '85 and move to another state. Now our son is moved in with us and our lives are put on hold.... "

- Family Member

" I feel there should be more psychotherapists who accept Medicaid.... Psychotherapy is important for the head injured. "

- Person with a head injury

" Someone should be concerned as much with the family in the beginning.... "

- Family Member

" Let's teach and inform the people of Massachusetts about head injuries and the complex future for the victims. "

- Family Member

" Programs need to be developed across the state that 'specifically' meet the needs of the head injured population. "

- Family Member

" There is so much to say, but this one sticks out. I went from program to program being evaluated or tested. I needed and wanted some help and through all these programs I attended and tests I took, no one ever told me what to do or where to go. I walked around in a cloud for three years after my accident, no one ever gave me any direction. "

- Person with a head injury

## SUMMARY OF NEEDS ASSESSMENT SURVEY

In order to get a direct indication of needs for services and to get an assessment of current functioning levels of the head-injured, a survey questionnaire was mailed to a cross-section of both the state's head injured population and professionals who work with this population. Since there is no list of all head injured in the state, identifying and sampling this population was a complex process. In order to get a range of input, several different groups were contacted. First, all referrals to the Statewide Head Injury Program (SHIP) were included. This group represented a perspective of seriously injured persons who were in contact with the state agency responsible for coordinating their receipt of services. Second, a sample from the membership list of the Massachusetts Chapter of the National Head Injury Foundation was included. Only those persons who were not part of the SHIP rolls were sampled. This group represented a perspective of relatively seriously injured persons (although members varied in the seriousness of the injury) who were not currently in contact with SHIP. Third, all head-injured cases that were seen at the University of Massachusetts Medical Center's Trauma Unit within a period of six months ago to three years ago were included. Clinical input was sought from three different sample groups as well. First, those who expressed an interest or participated in SHIP's Professional Collaborative were included. This group represents professionals from across the state in various disciplines who work with head injury survivors and their families. Second, individuals who are registered as professional members of the Massachusetts Chapter were surveyed. This group did not include clinicians who were also part of the SHIP sample. Third, questionnaires were sent to a number of hospitals and centers that provide inpatient and outpatient rehabilitation services to this population.

It is important to recognize that the data presented from this survey are not a good basis for determining either the yearly rate of occurrence of head injury nor the distribution of seriousness of injury within the population of head-injured, nor the total number of head-injured currently residing in the state. This information is obtained more accurately from the state's Uniform Hospital Discharge Data Set (UHDDS) and by extrapolating from national data.



The primary function of these data are to provide a picture of the current functioning and service needs of different groups of head-injured. Using the data about the six groups included in the survey will give a good representation of the needs of seriously injured persons as well as providing some indication of the proportion of seriously injured cases that are seen by hospitals in the state. The UMass Trauma Center sample also provides information about the needs of moderately and mildly injured persons.

#### RESPONSE RATES

In total, 1693 head injured persons and/or their families were mailed survey questionnaires (see Appendix A). These included 456 from the SHIP program, 551 from the Massachusetts Chapter of the NHIF, and 686 patients from the UMass Trauma Center. A total of 1031 questionnaires were returned for an overall response rate of 61 percent. The response rate varied somewhat depending on the sample source: 317 or 70 percent of the SHIP sample returned questionnaires; 264 or 48 percent of the Mass Chapter sample participated; and 450 or 66 percent of the UMass sample returned questionnaires. The somewhat lower response rate from the Massachusetts Chapter list reflects two realities: (a) the mailing addresses were older and hence a greater fraction were not delivered, and (b) some of the people on the list were not head-injured or family of head-injured, but rather people who were interested in the cause of the Head Injury Foundation. Beyond this, the somewhat lower response rates for the SHIP and UMass sample probably reflect the mobility of this population (again not having current addresses) and the reality that the injury and subsequent impairments make it difficult to fill out and return a survey. In general, however, the response from the head injured and their families, provides a wealth of information about the current functioning and needs of the head-injured. These response rates are summarized in TABLE 3.1.



TABLE 3.1

## Response Rates on Client Surveys for Each Sample Type

<u>CATEGORY</u>	<u>SHIP</u>	<u>MASS. CHAPTER</u>	<u>UMASS</u>
Sample	456	551	686
Questionnaires Returned	317	264	450
Response Rate	70%	48%	66%

A different questionnaire was developed for providers and sent to 172 SHIP Professional Collaborative members, 417 professional members of the Massachusetts Chapter and 46 professionals who were affiliated with hospital rehabilitation programs. Surveys were returned by 218 clinicians with an overall response rate of 37 percent. The response rate between sample groups varied greatly with a 55 percent return from the SHIP group, 28 percent from the Massachusetts Chapter and 41 percent from the hospital sample. The very low rate of response from the Massachusetts Chapter may again be reflective of the fact that a number of these professionals may not necessarily provide clinical services to this population or work with head-injured people at all, but rather are professionals interested in and supportive of the cause of the Head Injury Foundation in general. TABLE 3.2 below presents these response rates while the background of these providers is summarized in TABLE 3.3.

TABLE 3.2

Response Rates on Provider Surveys for Each Sample Type

<u>CATEGORY</u>	<u>SHIP</u>	<u>MASS. CHAPTER</u>	<u>HOSPITALS/ REHABILITATION PROGRAMS</u>
Original Sample	172	417	46
Nonsample	8	34	0
Revised Sample	164	383	46
Questionnaires Returned	92	108	19
Response Rate	55%	28%	41%

**TABLE 3.3**  
**Professional Background of Provider by Sample Source**

	SHIP	OTHER	TOTAL
<b>Professional Affiliation</b>			
Acute Care Hospital	17%	15%	16%
Rehab Hospital	27	26	26
Rehab Program	19	21	20
Outpatient Clinic	7	3	5
Nursing Home	4	10	8
Private Practice	11	6	8
Other	15	18	18
<b>Discipline of Provider</b>			
Psychologist	40	5	20
Speech Pathologist	15	16	16
Occupational Therapist	8	13	11
Physical Therapist	7	12	10
Nurse	3	11	8
Social Worker	7	11	9
Physician	7	8	7
Other	13	24	19
<b>County in Which Provider Practices</b>			
Suffolk	39	26	32
Essex	3	12	9
Middlesex	12	20	17
Norfolk	10	12	11
Plymouth	9	6	7
Worcester	9	7	8
Other	18	17	16
<b>Years Experience in Field of Head Injury</b>			
Less Than 2 Years	7	13	10
2-5 Years	43	44	43
6-10 Years	39	27	32
11 or More Years	12	17	15
<b>Mean Number of Head Injured Clients</b>	75	64	68
<b>Proportion of Clients Seen in Private Practice</b>	15	13	14



# DEMOGRAPHIC CHARACTERISTICS OF THE HEAD INJURED

Our data show that head injuries occur more often among males and more often among young persons between the ages of 6 and 29. The overall sample included 72 percent males and 28 percent females. The proportion of males in the SHIP sample was somewhat higher (82%), and somewhat lower in the Massachusetts Chapter sample (62%). These data are summarized in TABLE 3.4 below. These figures, however, correspond relatively well with national data and statewide data (UHDDS) which find that two-thirds of head injured persons are male. Our samples show about one-third are injured at school age and almost 40 percent are injured between the age of 19 and 29 for a total of almost three-quarters in these two age ranges. These distributions are slightly different among the samples with the UMass sample showing two-thirds in these two age ranges whereas in the SHIP sample we found about four-fifths in these two age ranges. Statewide data from the UHDDS show 52 percent of the head injured in these two age ranges. Therefore, our samples somewhat underrepresent injuries to preschoolers and persons injured over the age of 30. This distribution of age at injury can be seen in TABLE 3.5.

TABLE 3.4

## Head Injury by Gender by Sample Type

<u>GENDER</u>	<u>SHIP</u> <u>(N=302)</u>	<u>MASS</u> <u>CHAPTER</u> <u>(N=202)</u>	<u>UMASS</u> <u>(N=443)</u>	<u>TOTAL</u> <u>SAMPLE</u> <u>(N=947)</u>
Males	82%	62%	69%	72%
Females	18	38	31	28

TABLE 3.5

## Age at Injury by Sample Type

AGE	Sample Type		
	SHIP CLIENTS (N=291)	MASS CHAPTER (N=254)	UMASS (N=431)
0 - 2 years	1%	2%	4%
3 - 5 years	1	2	4
6 - 15 years	15	11	20
16 - 18 years	23	15	14
19 - 21 years	20	11	13
22 - 29 years	24	26	19
30 - 39 years	10	16	9
40 - 64 years	4	13	14
65+ years	1	4	3



The samples differ in the number of years post-injury (see TABLE 3.6). The UMass Trauma Center sample was designed to include only those injured in the past three years. For the SHIP and Mass Chapter samples approximately half were injured during the past five years and the other half greater than five years ago. In some cases people participated who had been injured more than 35 years ago. Because of the differences between the samples in distribution of age at injury and the differences in the number of years post-injury, we find current age distributions to be markedly different (See TABLE 3.7).

TABLE 3.6

## Number of Years Since Injury by Sample Type

NUMBER OF YEARS SINCE INJURY	Sample Type		
	SHIP CLIENTS (N=291)	MASS CHAPTER (N=254)	UMASS (N=431)
0 - 1 year	10%	2%	29%
2 years	17	10	46
3 years	10	11	23
4 - 5 years	18	26	1*
6 - 10 years	28	28	1*
11 - 53 years	16	22	0
Average Years Since Injury for Sample Types	6.2 yrs.	7.6 yrs.	2.0 yrs.

\* Individuals who sustained multiple head injuries - the most recent was within three-years.

TABLE 3.7

## Current Age By Sample Type

CURRENT AGE	Sample Type		
	SHIP CLIENTS (N=305)	MASS CHAPTER (N=260)	UMASS (N=442)
0 - 2 years	0%	0%	3%
3 - 5 years	0	1	3
6 - 15 years	3	3	19
16 - 18 years	5	4	8
19 - 21 years	13	8	14
22 - 29 years	44	25	24
30 - 39 years	24	28	11
40 - 64 years	11	24	14
65+ years	1	7	4

Head injured persons are less likely to marry. Census data for Massachusetts shows about 70 percent of adults over age 25 are married. In our samples of the head-injured we find fewer people married, particularly in the two samples that have a high proportion of severely injured persons. Only 16 percent of the SHIP clients, and 36 percent of the Massachusetts Chapter clients, over age 25 were married. The UMass Trauma Center sample with the majority of its people experiencing mild or moderate head injuries, had a higher rate of marriage, 48 percent, although this was still below the state average for this age group (See TABLE 3.8).

TABLE 3.8

Marital Status by Sample Type  
for Persons 25 or Older

<u>MARITAL STATUS</u>	<u>Sample Type</u>		
	<u>SHIP CLIENTS (N=190)</u>	<u>MASS CHAPTER (N=203)</u>	<u>UMASS (N=183)</u>
Married	16%	36%	48%
Separated	4	4	4
Divorced	15	17	15
Widowed	0	5	6
Never Married	65	38	27

Note: 1980 Census data for Massachusetts for persons 25-64 years old show 73% of males being married and 68% of the females being married.

It is not surprising to note that severe head injuries affect a person's employability. Only 24 percent of the SHIP clients and 40 percent of the Massachusetts Chapter clients over age 18 are currently working (see TABLE 3.9). Of those working, 52 percent of the SHIP group were in non-paying positions (see TABLE 3.10). Even more telling is the statistic which looks at those persons who were working full-time before the injury. Of the SHIP clients, 82 percent have not returned to work; 61 percent of the Massachusetts Chapter clients have not returned to work; and in the UMass Trauma Center sample 25 percent have not returned to work (see TABLE 3.11).

TABLE 3.9

Employment Status by Sample Type and Sex  
For Adults 18 Years or Older

CURRENT EMPLOYMENT STATUS	Sample Type and Sex					
	SHIP CLIENTS		MASS CHAPTER		UMASS	
	MALES (N=227)	FEMALES (N=47)	MALES (N=119)	FEMALES (N=73)	MALES (N=217)	FEMALES (N=92)
Currently Working	21%	11%	47%	29%	74%	60%
Not Working	79	89	53	71	26	40

TABLE 3.10

Employment Situation for Adults 18 or Older  
Who Are Currently Working  
by Sample Type and Sex

EMPLOYMENT TYPE	Sample Type and Sex					
	SHIP CLIENTS		MASS CHAPTER		UMASS	
	MALES (N=50)	FEMALES (N=4)	MALES (N=57)	FEMALES (N=20)	MALES (N=160)	FEMALES (N=54)
Full-Time, Paid	30%	--a	70%	55%	86%	38%
Part-Time, Paid	18	--a	14	40	13	58
Supervised	46	--a	14	5	1	4
Volunteer	6		2	0	0	0

a. Too few cases to present.

TABLE 3.11

Pre-and Post-Injury Employment Data by Sample Type  
for Adults 18 Years or Older at Time of Injury

<u>CURRENT WORK STATUS</u>	<u>PRIOR WORKING STATUS BY SAMPLE TYPE</u>					
	<u>SHIP CLIENT</u>		<u>MASS CHAPTER</u>		<u>UMASS</u>	
	Full- Time ( <u>N=125</u> )	Part- Time ( <u>N=21</u> )	Full- Time ( <u>N=123</u> )	Part- Time ( <u>N=25</u> )	Full- Time ( <u>N=184</u> )	Part- Time ( <u>N=31</u> )
Currently Working	17%	14%	38%	47%	71%	74%
Not Working	83	86	62	53	29	26



The data reveal that the majority of head injury survivors surveyed are living at home rather than in a hospital or long-term care facility (See Appendix C). Of those individuals 18 years of age or older who are not presently married, 76 percent of the SHIP clients, 57 percent of the Massachusetts Chapter and 66 percent of the University of Massachusetts sample are living at home with their families. These data are summarized in TABLE 3.12 below.

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TABLE 3.12

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Current Living Situation for Those  
18 Years of Age or Older and Unmarried by Sample Type

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CURRENT LIVING SITUATION	Sample Type		
	SHIP CLIENTS (N=161)	MASS CHAPTER (N=135)	UMASS (N=198)
Living Alone	18%	32%	19%
Living With Family	76	57	66
Living with Non-relatives	6	11	15

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Survey responses indicate that SHIP clients are more dependent on public assistance programs such as Medicaid (53%) as compared to the Massachusetts Chapter (22%) and the University of Massachusetts sample group (10%) (see TABLE 3.13). Providers have reported that over 43 percent of their payments come from Medicaid and Medicare (see Appendix D).

TABLE 3.13

## Sources of Financial Assistance by Sample Type\*

TYPE OF ASSISTANCE RECEIVED	Sample Type		
	SHIP CLIENTS (N=302)	MASS CHAPTER (N=253)	UMASS (N=421)
a. Own Medical Insurance	19%	36%	40%
b. Covered by Someone Else's Medical Insurance	22	22	44
c. Received Financial Settlement or Settlement Pending	27	35	29
d. Medicaid	53	22	10
e. Social Security	44	17	8
f. Social Security Disability Insurance	37	29	5
g. Medicare	31	25	5
h. Workers Comp.	3	5	4
i. Private Disability Insurance	3	6	2

\* Respondents were asked to check all sources of financial assistance, therefore, percentages add to more than 100.

A summary of demographic information on the sample groups can be found in TABLE 3.14 below.

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TABLE 3.14

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Summary of Demographic Comparisons of Three Sample Types

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<u>Demographic Characteristic/ Group</u>	<u>SHIP CLIENTS</u>	<u>MASS CHAPTER</u>	<u>UMASS</u>
Males	82%	62%	69%
Age 18 or less at Injury	40	29	42
Current Age 18 or less	7	7	30
Education of Adults: Some College or More	23	44	33
Marital Status of Adults Never Married	77	48	52
Currently Living at Home	68	82	97
Adult Employment Status: Currently Working	19	40	69

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NATURE OF HEAD INJURIES

Car crashes are the single leading cause of head injuries with almost half (46%) of the head-injured surveyed being involved either as a driver or passenger. When pedestrians who are hit by cars (10%) are added to the total the majority of the head injuries can be attributed to car crashes. These data correspond to data from a variety of other state and city studies nationwide. Falls are the next most common cause of head injuries for the population as a whole (11%). However for preschool-age children, falls are the leading cause of head injury (43%) and for persons over the age of 40, falls account for about one-quarter of the injuries (see TABLE 3.15). TABLE 3.16 below exhibits the distribution of injuries by month.

**TABLE 3.15**  
**Cause of Head Injury by Age at Injury**

CAUSE	0-5 (N=53)	6-15 (N=160)	16-21 (N=305)	22-29 (N=220)	30-39 (N=109)	40-64 (N=104)	65+ (N=25)	TOTAL SAMPLE (N=976)
Driving	0%	2%	34%	35%	44%	32%	40%	28%
Passenger In Car	9	19	29	15	7	10	12	18
Hit by Car Pedestrian	13	21	10	7	6	9	0	10
Motorbike	0	4	10	17	4	2	0	8
Bicycle	13	23	3	1	5	6	8	7
Boating/ Sports	2	6	2	0	2	3	4	3
Falls	43	18	4	10	6	22	28	11
Work-Related	0	0	2	5	8	9	0	9
Assault	0	0	4	7	6	3	4	4
Other	19	6	3	2	10	6	4	5

TABLE 3.16

Month Head Injury Occurred  
(N=964)

<u>Month</u>	<u>Proportion of Sample</u>
January	6%
February	7
March	7
April	9
May	13
June	11
July	8
August	8
September	10
October	7
November	6
December	8

The severity of the injuries sustained by the sample population varies from mild to severe. For the purposes of this report, the severity of a head injury has been defined by the duration of unconsciousness, with brief loss (< 1 hour) being equated with a mild injury; 1-24 hours loss equaling a moderate injury; and loss of consciousness > 24 hours constituting a severe injury. In extreme cases, death occurs from injuries. The focus of our study is the functioning and needs of those who survive head injuries. Using length of unconsciousness as a proxy assessment of the severity of the injury, and a loss of consciousness of 24 hours or more as a criterion for a severe injury, we find at least 80 percent of the SHIP clients, 59 percent of the Massachusetts Chapter clients, and 16 percent of the UMass Trauma Center sample to have sustained a severe head injury. These rates could be even higher because in some cases the person completing the survey did not know the length of unconsciousness. Sample data regarding length of unconsciousness are summarized in TABLE 3.17.



TABLE 3.17

## Duration of Unconsciousness by Sample Type

DURATION OF UNCONSCIOUSNESS	Sample Type			TOTAL SURVEYED (N=989)
	SHIP CLIENTS (N=303)	MASS CHAPTER (N=255)	UMASS (N=431)	
No Loss	3%	8%	18%	11%
Brief Loss	1	12	32	17
1 - 24 Hours	2	7	19	11
24 Hours or More	80	59	16	47
Still in Coma	1	2	1	1
Length Uncertain	8	8	9	8
Don't Know	4	4	6	5

Providers report that 64 percent of those they serve have suffered moderate to severe head injuries (See Appendix D).

One factor that is clear from our data is that the severity of the injury is highly correlated with the cause of the injury. Motor vehicle related incidents are three to four times as likely to cause a severe head injury than falls which are the next most frequent cause (see TABLE 3.18).

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**TABLE 3.18**  
**Duration of Unconsciousness (If Known) by Cause of Injury**

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<b>Duration of Unconsciousness</b>	<b>No Loss</b>	<b>Brief</b>	<b>1-24 Hours</b>	<b>More than 24 Hours Regained</b>
DRIVING (N=239)	9%	17%	15%	60%
PASSENGER (N=168)	7	17	14	63
PEDESTRIAN (N=93)	10	9	9	73
MOTORBIKE (N=70)	6	13	7	74
BICYCLE (N=57)	14	33	14	40
SPORTS (N=28)	11	36	14	39
WORK (N=21)	26	37	11	26
ASSAULT (N=32)	6	21	18	55
FALL (N=93)	32	35	12	21
OTHER (N=49)	24	24	12	39

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It is important to understand that the effectiveness of seat belts to prevent a head injury in the first place cannot be determined from our sample because we only have data from people who sustained head injuries. We are unable to ascertain how many avoided head injuries altogether because they were wearing their seat belts. However, of those involved in car accidents only 18 percent of the head-injured were wearing seat belts. The data also show that among persons with mild or moderate head injuries, 23 percent were wearing seat belts. Among the severely head injured 16 percent were wearing belts. TABLE 3.19 presents seat belt usage among the sample groups.

Alcohol and drugs become another area of concern in understanding the causes of head injuries. The data show that 40 percent of those involved in car accidents or motorcycle accidents had used drugs or alcohol prior to the accident and for falls, 19 percent reported alcohol or drug use prior to the accident (see TABLE 3.20).



**TABLE 3.3**  
**Professional Background of Provider by Sample Source**

	SHIP	OTHER	TOTAL
<b>Professional Affiliation</b>			
Acute Care Hospital	17%	15%	16%
Rehab Hospital	27	26	26
Rehab Program	19	21	20
Outpatient Clinic	7	3	5
Nursing Home	4	10	8
Private Practice	11	6	8
Other	15	18	18
<b>Discipline of Provider</b>			
Psychologist	40	5	20
Speech Pathologist	15	16	16
Occupational Therapist	8	13	11
Physical Therapist	7	12	10
Nurse	3	11	8
Social Worker	7	11	9
Physician	7	8	7
Other	13	24	19
<b>County in Which Provider Practices</b>			
Suffolk	39	26	32
Essex	3	12	9
Middlesex	12	20	17
Norfolk	10	12	11
Plymouth	9	6	7
Worcester	9	7	8
Other	18	17	16
<b>Years Experience in Field of Head Injury</b>			
Less Than 2 Years	7	13	10
2-5 Years	43	44	43
6-10 Years	39	27	32
11 or More Years	12	17	15
<b>Mean Number of Head Injured Clients</b>	75	64	68
<b>Proportion of Clients Seen in Private Practice</b>	15	13	14





TABLE 3.20

Cause of Injury as Related to Drug or Alcohol  
Use (24 Hours Prior to Accident)  
for Persons 16 Years Old or Older

<u>CAUSE OF INJURY</u>	<u>N</u>	<u>USED DRUGS OR ALCOHOL (N=257)</u>	<u>DID NOT USE DRUGS OR ALCOHOL (N=435)</u>
Motor Vehicle Accident	479	41%	59%
Driver of Car	251	41	59
Passenger in Car	163	40	60
Motorbike/Motorcycle	65	42	58
Pedestrian Hit by Car	94	15	85
Bicycle	68	4	96
Sports/Boating	30	10	90
Work-Related	31	13	87
Falls	109	19	81
Assault	32	41	59
Other	52	17	83

### RESULTING IMPAIRMENTS FROM HEAD INJURIES

Head-injured persons and their families must deal with a wide range of residual problems. As reviewed in Chapter I, impairments can be physical, cognitive, behavioral and/or psychological. The nature and frequency of impairments for the sample population are reviewed below and summarized in Appendix E and TABLES 3.23-3.26.

Given the significant amount of impairment that results from a head injury, even with mild head injuries, and given that the most frequent cause of head injuries is motor vehicle accidents, it is important to pose the question as to the effectiveness of seat belts in reducing impairment levels. Again the data presented in the previous section cannot be used to judge in how many cases seat belts kept people from being injured at all. However, it was clear that on almost every impairment indicator, persons wearing belts survived with less impairment than persons not wearing belts (see TABLE 3.21). In addition passengers not wearing belts were even more impaired than drivers not wearing belts.

Physical Impairments. Visual impairments were reported by 40 percent of the total sample. Fifty-two percent of those severely injured reported that they experienced visual impairments. Two percent of the severely injured reported they were blind. Thirteen percent reported that they have hearing impairments. The proportion of head-injured reporting hearing problems does not appear to vary with severity of the injury.

The other major physical impairment which is caused by head injuries is the ability to walk. Twenty-four percent of the sample reported some mobility impairment. This increases to 35 percent among the severely injured with 14 percent being wheelchair-bound.

These physical impairments affect the ability of head injury survivors to carry out basic activities of daily living-feeding, dressing, bathing and toileting. In particular, severe head injuries affect the ability to carry out these daily functions. Of the severely injured 14 percent require assistance with eating; 26 percent with dressing; 29 percent with bathing; and 20 percent with toileting. Of the sample group 2.4 percent are totally dependent in all activities of daily living, while an additional 1.7 percent need total care in three out of four areas (see TABLE 3.22).

TABLE 3.21

Frequency of Impairment as Related to  
Seat Belt Usage

IMPAIRMENT INDICATOR	Percentage With Some Impairment		
	Driver Wearing Seat belt (N=53)	Driver No Seat belt (N=188)	Passenger No Seat belt (N=147)
a. Basic Activities of Daily Living	15%	19%	21%
b. Sensory/Mobility	13	45	50
c. Self-Preservation	23	35	42
d. Drug or Alcohol Abuse	11	22	23
e. Neurobehavioral	35	44	57
f. Neuropsychiatric	55	64	75
g. Personality Disorder	46	59	66
h. Cognitive Disorder	62	71	80

TABLE 3.22

Number of Activities of Daily Living for Which Injured  
is Totally Dependent

NUMBER OF ACTIVITIES OF DAILY LIVING REQUIRING TOTAL ASSISTANCE*	Sample Type			
	SHIP CLIENTS (N=262)	MASS CHAPTER (N=220)	UMASS (N=365)	TOTAL SURVEY (N=847)
NONE	88%	89%	98%	92.4%
1	4.0	3.0	0	1.9
2	3.0	3.0	0	1.7
3	2.0	2.0	1.0	1.7
4 (Currently Conscious)	2.0	2.7	0.5	1.0
4 (Currently Unconscious)	2.0	0.5	0.3	1.4

\* Activities included were dressing, feeding, bathing, and  
toileting.

Cognitive Impairments. Probably the most widespread effect of head injury is the disruption of cognitive functioning. Cognitive impairments are found among those who have mild injuries as well as those who are more severely injured. Fifty percent of those with mild or moderate head injuries reported some impairment in cognitive functioning, whereas 94 percent of the severely injured exhibit cognitive deficits. For instance, among the SHIP clients 73 percent reported difficulty in paying attention or concentrating and 72 percent reported difficulty with learning new information. These findings are substantiated by providers who report that approximately 42 percent of their clients had mild cognitive impairments, while almost 60% had moderate to severe cognitive dysfunction (see TABLE 3.24).

Twenty-one percent of the total sample exhibit communication impairments. Providers report that 48 percent of the head injury survivors they have seen have moderate to severe communication disorders (see TABLE 3.24).

Psychological Impairments. Depression is one of the primary psychological problems that emerge after the injury. Over half of the severely injured currently report being depressed, or lonely, or having difficulty making or keeping friendships. Although less likely to be a problem for the milder forms of head injury, psychological problems do exist for some. Nearly 20 percent of the UMass sample reported problems with depression. Twenty-three percent of those individuals seen by providers have exhibited psychological disorders (see TABLE 3.24).

Behavioral Problems. Closely related to the presence of psychological impairments are a wide range of behavioral problems which are experienced by many head injury survivors. About a quarter of the moderately and severely injured report current problems with alcohol or drug abuse. Among the SHIP clients 15 percent report a suicide attempt since their injury. Forms of aggressive behavior reported range from assaulting others to damaging property, while disinhibition may be expressed through sexually inappropriate behaviors. These occur less frequently than other problems, but are still seen in approximately 5 percent of the severely injured. Approximately 42 percent are estimated by providers to have moderate to severe behavioral dysfunction (see TABLE 3.24).

Other behavioral problems manifest themselves as impaired interpersonal and social skills. For instance, about 50 percent of the severely injured and 20 percent of less severely injured experience difficulty in responding to feedback from supervisors. About 40 percent of the severely injured engage in inappropriate social conversation when talking in small groups.



TABLE 3.23

## Summary of Specific Impairment Situations by Sample Type

IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=305)	MASS CHAPTER (N=260)	UMASS (N=442)
a. Blind	3%	2%	0%
b. Visually Impaired	56	48	19
c. Deaf/Hearing Impaired	14	20	11
d. Nonambulatory	22	18	2
e. Communication Impairments	41	28	4
f. Current Substance Abuse	22	21	11
g. Suicide Attempt Since Injury	15	10	2
h. Depression	52	61	24
i. Assaults Others -- "often," "very often"	3	2	1
j. Destroys Property "often," "very often"	3	2	1
k. Self-Injurious Behavior -- "often," "very often"	3	1	0
l. Molests Others -- "often," "very often"	2	0	0
m. Exposes Self Sexually "often," "very often"	1	0	0
n. Sexually Promiscuous -- "often," "very often"	3	3	1



TABLE 3.24

Providers' Estimates of Frequency of Impairment  
in Their Head-Injured Clients  
(N = 218 Providers)

<u>TYPE OF IMPAIRMENT</u>	<u>PERCENTAGE OF CLIENTS WITH IMPAIRMENT</u>
a. Mild Behavioral Dysfunction	51%
b. Moderate to Severe Behavioral Dysfunction	42
c. Mild Communication Disorder	44
d. Moderate to Severe Communication Disorder	48
e. Mild Visual Impairment	31
f. Moderate to Severe Visual Impairment	22
g. Mild Cognitive Impairment	42
h. Moderate to Severe Cognitive Impairment	59
i. Active Substance Abuse	24
j. Arrested for Criminal Behavior	11
k. Psychiatric Disorder	23
l. Medical Problems Requiring Frequent Follow-up	39

TABLE 3.25

Comparisons of Frequency of Various Conditions  
Existing Pre- and Post-Injury

CONDITION PRE- & POST-INJURY	Sample Type		
	SHIP CLIENTS (N=311)	MASS CHAPTER (N=260)	UMASS (N=443)
a. Criminal Record			
Pre-Injury Only	6%	2%	3%
Pre- & Post-Injury	3	0	1
Post-Injury Only	5	7	2
b. Psychiatric Disorder			
Pre-Injury Only	3	0	0
Pre- & Post-Injury	3	2	1
Post-Injury Only	33	33	5
c. Suicide Attempts			
Pre-Injury Only	3	1	1
Pre- & Post-Injury	2	0	1
Post-Injury Only	14	9	1
d. Depression			
Pre-Injury Only	3	2	1
Pre- & Post-Injury	5	5	5
Post-Injury Only	47	56	19
e. Alcohol Abuse			
Pre-Injury Only	15	7	5
Pre- & Post-Injury	6	9	4
Post-Injury Only	7	7	3
f. Drug Abuse			
Pre-Injury Only	12	4	1
Pre- & Post-Injury	5	4	2
Post-Injury Only	6	5	3

TABLE 3.26

Percentage of Impairment as Related to  
Severity of Injury\*

IMPAIRMENT INDICATOR	Severity of Head Injury		
	MILD (N=270)	MODERATE (N=106)	SEVERE (N=459)
a. Basic Activities of Daily Living	11%	8%	32%
b. Sensory/Mobility	32	36	69
c. Self-Preservation	13	19	53
d. Drug or Alcohol Abuse	9	24	25
e. Neuro-Behavioral	29	39	61
f. Neuro-Psychiatric	41	49	86
g. Personality Disorder	40	47	79
h. Cognitive Disorder	51	53	94

\* Severity of injury based on reported length of unconsciousness with brief loss (less than 1 hour) = mild, 1 - 24 hours loss = moderate, and more than 24 hours = severe.

SERVICE NEEDS

Given the range of problems caused by head injuries, it is not surprising to find a corresponding by wide range of service needs which is positively correlated with the severity of the injury.

For all types of services included in our survey, there were gaps in service delivery. Severely injured persons were not getting all the services that they needed. For the severely injured the services with the largest indication of "unmet needs" (between 20 and 35 percent unmet) are:

- a. Pre-vocational training
- b. Vocational training
- c. Vocational counseling
- d. Vocational placement
- e. Leisure or recreational services
- f. Financial assistance
- g. Family counseling
- h. Family training in behavioral management techniques
- i. Day programs
- j. Transportation to various programs
- k. Community residence with live-in staff
- l. Community residence with part-time staff

The distribution of unmet service needs can be found in TABLE 3.27 and TABLE 3.28. Even those who sustained mild head injuries reported unmet needs in a number of service areas (see TABLE 3.27).

TABLE 3.27

Percentage of Sample Reporting Unmet Needs\* for Various  
Types of Services by Severity of Head Injury

TYPE OF SERVICE NEEDED	Severity of Head Injury		
	MILD (N=270)	MODERATE (N=103)	SEVERE (N=421)
a. Physical Therapy	5%	7%	7%
b. Occupational Therapy	5	9	10
c. Speech or Language Therapy	3	3	5
d. Psychotherapy or Psychological Counseling	6	11	15
e. Vocational Assessment	6	12	21
f. Pre-vocational Training	4	8	25
g. Vocational Training	7	10	31
h. Vocational Counseling	8	10	30
i. Vocational Placement	7	10	35
j. Special Mobility Equipment	1	0	7
k. Communication Device	2	1	4
l. Home Modifications	1	1	5
m. Respite Care	2	0	12
n. Visiting Nurse	2	1	4

TABLE 3.27 (Cont'd)

Percentage by Sample Reporting Unmet Needs\* for Various  
Types of Services by Severity of Head Injury

TYPE OF SERVICE NEEDED	Severity of Head Injury		
	MILD (N=270)	MODERATE (N=103)	SEVERE (N=421)
o. Personal Care Attendant	2%	2%	6%
p. Frequent Medical Follow-up	6	8	15
q. Special Education	4	3	18
r. Interpreter	0	0	1
s. Leisure or Recreational Services	7	7	36
t. Financial Assistance	11	14	23
u. Family Counseling	7	8	22
v. Family Training in Behavioral Management	7	9	22
w. Day Program	5	8	26
x. Transportation to Programs	7	9	26

\* Unmet Needs include services needed and known but not yet received, or services needed but not known where to receive them.



TABLE 3.28

Likelihood of Need of Various Living Settings  
in the Future by Sample Type for Persons 18 or Older

TYPE OF LIVING SITUATION	Need			
	NOT AT ALL LIKELY	A LITTLE LIKELY	SOMEWHAT LIKELY	VERY LIKELY
Community Residence With 24-Hour Live-In Staff				
SHIP Clients (N=260)	50%	9%	10%	30%
Mass Chapter (N=219)	73	7	8	12
UMASS (N=296)	98	2	0	1
Community Residence With Part-Time Staff				
SHIP Clients (N=263)	62	11	13	15
Mass Chapter (N=216)	71	13	8	8
UMASS (N=295)	96	3	1	0
Nursing Home or Long-Term Care Facility				
SHIP Clients (N=262)	76	3	7	14
Mass Chapter (N=217)	76	5	7	12
UMASS (N=296)	97	2	0	1

The survey responses indicated that of those identifying unmet needs, a greater number were unaware of how and where to access these services (see Appendix F). This has implications for the need for state agencies to develop more extensive outreach strategies to educate potential consumers on the services they do provide. Providers also indicated in their assessment of agency response to the needs of the head injured that fiscal limitations, staffing constraints, lack of clinical expertise and limited service options all contribute to inadequate service delivery to this population (see TABLE 3.29).

Providers were asked to estimate the percentage of unmet needs within the population of head injury survivors they have seen in their clinical practices. The greatest areas of need (greater than 30 percent) were as follows:

- a. Vocational Placement
- b. Vocational Training
- c. Vocational Counseling
- d. Psychotherapy
- e. Peer Counseling
- f. Leisure/Recreation Services
- g. Day Programs .
- h. Transportation
- i. Financial Assistance
- j. Family Counseling
- k. Family Training in Behavior Management
- l. Community Residence

These data are summarized in TABLE 3.30 and TABLE 3.31.

TABLE 3.29

## Provider Experience With Referrals to Various State Agencies

AGENCY	% PROVIDERS MAKING REFERRALS (N=218)	SOME REFERRALS RECEIVED INADEQUATE SERVICES	Reasons for Inadequate Services			NO APPROPRIATE SERVICES FOR HEAD INJURED
			FISCAL	INSUFFICIENT STAFF	CLINICAL EXPERTISE	
a. Mass Rehab Commission	33%	61%	33%	19%	44%	58%
1. Independent Living Program	64	63	36	25	59	66
2. Voc. Rehab. Program	19	51	53	63	26	16
3. Home Maker/Chore Program						
4. Personal Care Attendant Program	23	59	26	57	52	26
5. Statewide Head Injury Program	57	71	89	37	11	32
b. Mass Commission for the Blind						
1. Independent Living Program	15	44	25	25	33	67
2. Vocational Rehab Program	21	53	46	41	59	50
c. Dept. of Mental Health	39	84	43	34	60	69
d. Dept. of Mental Retardation	13	72	35	35	47	77
e. Mass Commission for the Deaf and Hard of Hearing	4	17	*	*	*	*
f. Dept. of Social Services	35	58	37	50	55	50
g. Dept. of Public Health	16	50	63	38	69	63
h. Dept. of Youth Services	9	81	39	46	62	62
i. Office for Children	15	50	20	20	67	60
j. Dept. of Ed. — Spec. Ed.	38	60	20	34	68	66

\* Too few cases to present data.

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**TABLE 3.30**  
**Percentage of Clients Needing But Not Receiving Specialized**  
**Services According to Providers**

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<b>SERVICE</b>	<b>PERCENTAGE NEEDING</b>
Physical Therapy	9%
Occupational Therapy	12
Speech-Language	11
Psychotherapy	31
Peer Counseling	36
Training in Independent Living	25
Vocational Assessment	27
Pre-Vocational Counseling	28
Vocational Counseling	30
Vocational Training	32
Vocational Placement	37
Special Mobility Equipment	14
Mobility Training	11
Communication Device	11
Motor Vehicle Modifications	13
Home Modifications	15
Other Adaptive Equipment	14
Respite Care	26
Visiting Nurses	12
Personal Care Attendant	15
Frequent Medical Follow-up	12
Special Education Services	18
Interpreter	6
Leisure/Recreation Services	32
Day Program - Full-time	33
Day Program - Part-time	31
Transportation	31
Financial Assistance	34
Legal Assistance	21
Family Counseling	34
Family Training in Behavior Management	37
Homemaker/Chore Assistance	20
Community Residence/24-hr Supervision	35
Community Residence/ Part-time Supervision	30
Cooperative Living Apartment	29
Nursing Home or Long-Term Care	15
Case Management	26
Individual Advocacy	26

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TABLE 3.31

Providers' Assessment of  
Clients' Living Situation

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Situation Currently Inappropriate	31%
Clients Would be Appropriate for	
Independent living	18*
Living with family at home	31
Partial supervision	3
24-hr supervised community residence	33
Nursing home/long-term care facility	22

\* Total is greater than 100% due to independent estimations and averaging calculations.

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## Chapter IV



HEAD INJURY: PRIMARY PREVENTION IS OUR BEST HOPE

CAREY AZZARA, M.A.  
Assistant Director  
Statewide Comprehensive Injury Prevention Program (SCIPP)  
Massachusetts Department of Public Health



"... The reversal of the mandatory seat belt law was unconscionable and irresponsible. I am certain that if I were not wearing a seat belt I would have been severely injured or dead. "

- Person with a head injury

" Prevention is the key - anyone with head injury or a family member with a head injury would never vote against the seat belt law... "

- Family Member

" My accident occurred when our bike was struck by a car. It killed my husband. ... Because I was wearing a helmet I only suffered minor head injuries... "

- Person with a head injury





## INTRODUCTION

Severe head injury in Massachusetts, as in other states, has increasingly been recognized as a major health problem. The head injured person often suffers psychological and financial difficulties as well as the more obvious medical problems. Even minor head injuries may cause substantial losses of work days and school days, memory dysfunction and require medical follow-up for months or years.

Estimates of the magnitude of the head injury problem have varied widely depending upon definitions, sampling methods and the assumptions underlying extrapolations to specific populations. Determining the incidence of severe head injury and estimating the associated costs of care for a defined population are essential steps in the process of developing policies and programs to prevent head injuries through the use of injury control strategies.

As was discussed in Chapter 1 of this report, data derived from the Uniform Hospital Discharge Data Set (UHDDS) revealed that over the course of a three-year period, 1984-1986, over 23,000 individuals were discharged alive from Massachusetts hospitals with a diagnosis of traumatic brain injury. Estimated acute care hospital cost alone (Chapter II) totaled an average of \$45.5 million per year.

## PREVENTION

The fundamental tasks of injury control are to prevent agents\* from reaching people in amounts that can cause injury, and to minimize the consequences of injuries that do occur. Haddon and Baker (1981) (1) suggested the following interrelated approaches to injury prevention:

- (1) Prevent or reduce the amount of agent available to cause an injury - Limit the speed of motor vehicles.
- (2) Prevent inappropriate release of the agent - Prevent driving, boating or swimming after drinking.
- (3) Modify the release of the agent - Place safety valves on boilers.
- (4) Separate host from agent in time, space or with physical barriers - Use helmets and padded clothing; mandate the use of seat belts; place fences around pools.

\* The term "agent" refers to the various forms of energy (i.e., mechanical, heat, electricity, chemicals, and ionizing radiation).

- (5) Modify surfaces and basic structures - Install air bags; engineer lampposts and signposts to yield upon impact; soften surfaces under playground equipment.
- (6) Increase resistance to injury - Pay more attention to warm-up and cool-down practices when engaging in sports activities.

As the approaches and examples above suggest, many potential strategies exist for the prevention and control of injuries. Although all forms of countermeasures should be used, passive measures (i.e., modification of the environment) should be given preference whenever feasible. Product design requirements to improve playground surfaces and equipment are more effective in reducing head injuries than relying on caregivers to exercise constant supervision. The impact that passive measures and legislative interventions can have and have had on the incidence of injuries is often underestimated. The most successful approaches to reducing injuries from any cause have involved a combination of strategies: educational/behavioral change programs, legislative initiatives, the application of technology, and enforcement of regulations. To be successful, these must be applied systematically and consistently over time.

#### PREVENTION PRIORITIES FOR REDUCING THE INCIDENCE OF HEAD INJURIES

##### Falls

To date, few intervention strategies for the prevention of falls have been attempted. One explanation is that these injuries have numerous causes and there is limited knowledge concerning the circumstances of their occurrence. To make an impact on the fall injury rate, interventions must be designed that protect the highest-risk groups.

While falls among the elderly are a significant problem, we should not lose sight of the fact that all age groups are affected by falls. Environmental hazards such as poor lighting of stairwells, lack of handrails, handrails that are difficult to grab, unmarked steps or curbs in public spaces and buildings, and slippery walking surfaces need to be identified and remedied.

##### Universal Safety Belt Legislation and Enforcement

Two major activities are needed for further progress in reducing motor vehicle collisions that cause head injuries:

- Work with police departments to ensure enforcement of existing legislation.
- Work with state legislatures and seat belt coalitions to ensure passage of universal seat belt laws requiring all passengers to be protected; and ensure that these laws are worded so as not to endanger the implementation of the national air bag standard.

The 1986 repeal of the adult safety belt legislation in Massachusetts illustrates the need to increase efforts to demonstrate the need for and the effectiveness of occupant restraints. Similar to helmet laws for motorcyclists, a compelling argument for motor vehicle occupant restraint requirements rests on the fact that substantial societal costs are incurred when motor vehicle occupants are injured or killed in collisions. Passage of seat belt laws protecting older children (i.e., between 13 and 18 years of age), incentives for purchasing automobiles with automatic restraints and air bags, enforcement of traffic safety laws, and initiatives that promote the use of safety belts among all Massachusetts residents are all strategies which should be pursued.

#### Motor Vehicle Accidents Among Teens

Nationally, drivers under the age of 25 make up only 22 percent of all registered drivers, but they represent 40 percent of all accident-involved drivers. Sixteen-year olds have higher crash rates than any other age. Teens are most likely to be killed in nighttime crashes, in cars driven by other teens, and while under the influence of alcohol, according to the Insurance Institute for Highway Safety.

Similar patterns exist for youths in the Commonwealth. As a leading cause of head injury, motor vehicle collisions outrank all other injuries for all age groups with the sole exception of falls. Thus, it is apparent that to appreciably affect motor vehicle head injury rates, public policy and education need to address this population of drivers who are at relatively high risk.

The Insurance Institute for Highway Safety (IIHS) cites three legislative measures, applicable to the Commonwealth, that have proven effective in reducing the burden of teen motor vehicle accidents. The first is the enactment and enforcement of curfew laws to prevent teens from driving during the hours when they are most likely to be injured. Massachusetts law restricts drivers under 18 years old with learners permits from driving between the hours of 1:00 a.m. and 5:00 a.m., unless accompanied by a parent or guardian licensed to drive in Massachusetts.



Secondly, IIHS suggests that the minimum age of licensure be raised to 17. Having completed a driver training course, at the age of 16, Massachusetts residents are eligible for a learners permit, without driver training, a permit can be obtained at age 16½. Finally, the use of safety belts should be required of all teens. Nationally, safety belts are used by only 10 to 15 percent of all drivers, but the IIHS states that the usage among teens, the group at highest risk of involvement in a motor vehicle collision, is much lower. The teenage population of the Commonwealth is not covered by the Child Restraint Law (Mass. law requires all children 12 years old and under to be fastened in a properly adjusted safety seat or seat belt) and yet is also too young to be considered adults capable of legally choosing to use safety belts. Therefore, a politically feasible and sound injury-prevention measure is to require that all children and adolescents use safety belts, including drivers under the age of 18, as a necessary requirement for the privilege of driving before they reach adulthood.

### Bicycles and Other Sports

The single most important prevention strategy for the reduction of head injuries among bicycle riders is the proper use of helmets. Bicyclists, especially when traveling in traffic, are at very high risk of head injury. Their lack of protection and the powerful mechanical forces that motor vehicles can deliver combine to create extremely hazardous conditions for cyclists. Games, such as baseball and hockey which use projectiles that move at high speed, and contact sports like football place these participants at risk for head injury. Helmets, properly maintained impact absorbing playing surfaces, and coaching practices that emphasize injury prevention are all strategies that can reduce the incidence of head injury.

### Intentional Injuries

Current estimates suggest that one third of the injury fatalities in the U.S. are due to intentional human behavior; in Massachusetts 27.8 percent of the injury fatalities were intentionally inflicted. Violence has traditionally been defined as a criminal justice problem, and only recently has it also been recognized as a major public health problem.

Studies have shown that 65 percent of murders result from arguments that escalate to physical violence, and 54 percent of all homicide victims were acquainted with their assailants. (2) The "intimate" characteristics of acquaintance-violence render it unlikely to be affected by the punitive, after-the-fact interventions that have traditionally been handled by the criminal justice system. Prevention of deadly violence will require an interruption in the current relationship between available weapons and assaultive acts. Emphasis

should be placed on factors that contribute to the use of the most lethal weapons. Handgun control, for example, needs to be given a higher priority. The liability of manufacturers and the behavior of individuals must be considered to diminish the harm caused by firearms.

The role of intent in violence suggests that behavioral change must become a more central issue in its prevention. Violence must be conceptualized as a public health problem in the same manner as heart disease, cocaine abuse and drunk driving have been. The public health and criminal justice communities need to merge paths in tackling the problem of intentional injuries.

#### SUCCESSFUL PREVENTION STRATEGIES

Programs have demonstrated that interventions employing the principles of prevention outlined earlier are indeed efficacious and lead to declines in injury rates.

A health policy analysis in 1984 reported that motor vehicle fatalities could be decreased by 50 percent through improvement of vehicle safety engineering, highway safety development, occupant restraint usage and a decline in drunk driving, saving 20,000 lives per year.<sup>(3)</sup> Requiring the use of safety belts is a second example of the application of injury control strategies that both create a barrier to injury and increase the resistance to injury. It is estimated that, nationally, properly worn safety belts could prevent over 40 percent of the front seat motor vehicle occupant fatalities which would otherwise have occurred.<sup>(4)</sup> It has also been estimated that if safety belt usage across the country were raised to 40 percent from the 12.5 percent figure in 1983, then annually at least 3,000 fewer traffic deaths would occur nationwide.<sup>(5)</sup>

Latimer and Lave in a preliminary analysis of the effects on fatalities and injuries from the New York State mandatory safety belt law (January 1, 1985) estimated that during the first six months' application of the law 220 fatal, 1,500 severe, 4,600 moderate, and 2,600 minor injuries were averted across the state.<sup>(4)</sup> State officials also pronounced the law a success, based on the fact that the number of fatalities in the state during the first months of 1985 was lower than during the same months one year earlier, and also lower than the average during the same months over the previous five years. Moreover, a comparison of New York to neighboring states without occupant restraint laws revealed a nine percent traffic fatality decline in the law's first nine months.

When children's fatal falls in New York City were studied, researchers found that such fatalities resulted mainly from falls from windows in multistory buildings. Fatal falls of children were reduced substantially by an intervention program that combined distribution of window coverings, education regarding the problem, and required use of the coverings by landlords. (Ref. Bergner, L. Environmental factors in injury control: Preventing falls from heights, pp. 57-60. In A.B. Bergman, Ed. Preventing Childhood Injuries. Report of the 12th Ross Round Table Critical Approaches to Common Pediatric Problems. Columbus, Ohio: Ross Laboratories, 1982.)

### CONCLUSION

The prevention strategies for head injuries discussed above only highlight specific areas of injury control that need immediate attention. Falls, motor vehicle accidents, intentional injuries, and sports are the leading causes of head injury. For each cause there are prevention strategies which are either known to be effective or ready to be evaluated. Yet, limited attention has been devoted to these four problem areas. It is important that future efforts in injury control and prevention place a high priority on these areas.



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## Chapter V



NON-TRAUMATIC BRAIN INJURIES:  
EPIDEMIOLOGICAL ASPECTS AND MAJOR SEQUELAE

FRANCESCA A. LAVECCHIO, Ph.D.  
Chief Neuropsychology Consultant  
Statewide Head Injury Program





" I find nothing out there geared to viral brain damage. Everything is funding for traumatic brain injury. What are we to do? "

- Family Member

" There are some people who 'fall between the cracks' e.g., people who have had brain tumors... whose functioning and behaviors parallels that of a head injured person rather than someone who is retarded... "

- Family Member



## INTRODUCTION

Acquired brain injury can result from a variety of causes, in addition to trauma. In this chapter, the major classifications of neurological disease, with the exception of peripheral nerve and spinal cord disorders, are reviewed with respect to their epidemiology, age of onset, and major sequelae. In an effort to determine the annual occurrence of these conditions, an analysis of information derived from the Uniform Hospital Discharge Data Set (UHDDS) was completed for those disorders where hospitalization during the acute stage was likely. The International Classification of Diseases (9) codes (ICD codes) selected for the purpose of estimating the annual incidence of neurological disorders were those designated specifically as brain injury codes. Those codes known, or suspected, to be associated with some degree of brain damage (e.g., cardiac arrest) within a specific category of neurological disorder were also included.

Unfortunately, for many central nervous system (CNS) disorders, the UHDDS does not provide adequate information with respect to annual incidence. For example, unless hospitalized, individuals who exhibit congenital disorders are not included in these data. Also, as with traumatic brain injury (TBI), those individuals who exhibit mild symptomatology, who may have been seen on an out-patient basis, are also not represented.

Disorders for which statistics derived from the UHDDS were not representative are described with respect to their clinical characteristics and epidemiological data derived from regional studies or studies of defined populations.

## NEUROVASCULAR SYNDROMES

### DEFINITION

The clinical syndrome which results when the vascular (blood) supply to the brain is disrupted or blocked is referred to as a stroke. Neurovascular syndromes refer to any neurological disorders which are precipitated by compromised circulation of oxygenated blood within the central nervous system.

There are basically two types of strokes:

- a) Ischemic-occlusive stroke which results from an internal blockage of a blood vessel.
- b) Hemorrhagic stroke which results from the spontaneous rupture of a blood vessel, which is often precipitated by the combination of hypertension and a structural abnormality (e.g. aneurysm, or abnormal dilation of an artery).

Ischemic-occlusive strokes can be caused by a blood clot (thrombosis), foreign body (embolus), or atherosclerosis. With respect to hemorrhagic strokes, bleeding may occur within the brain (intraparenchymal) or into the space between two coverings (meninges) of the brain (subarachnoid space).

The stroke syndrome consists of a cluster of neurological symptoms which are characterized by a sudden onset and which persist for more than 24 hours. These symptoms largely relate to the site of the occlusion (i.e. distribution of a particular artery), but, in the case of a hemorrhagic stroke, may reflect the extent and magnitude of the bleeding episode. The term infarct refers to the tissue or brain damage which results from a neurovascular lesion.

The term transient ischemic attack (TIA) refers to a sudden focal neurological deficit (e.g., language impairment), which resolves within a 24-hour period. The TIA syndrome characteristically results from an embolic event or compromised focal blood flow. Although an episode of short duration, the occurrence of a TIA is often indicative of a more diffuse or significant cerebrovascular problem.

### EPIDEMIOLOGY (NATIONAL)

Epidemiology studies performed by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) have demonstrated that stroke is the most common neurological disorder in the United States. The overall incidence is 1.8/10,000 and prevalence, 794/100,000. However, the incidence varies with age. For individuals under the age of 35, the incidence is 1/10,000, while for those over 75 years of age, the incidence is greater than 100/10,000 (1).

In 1975 (NINCDS study) 194,038 individuals died of stroke complications. Mortality risk is related to several factors:

- a) type of stroke: hemorrhagic >> ischemic-occlusive
- b) loss of consciousness: comatose >> non-comatose
- c) increased age.

The most common type of stroke is of the thrombotic variety. Predisposing risk factors associated with stroke include the presence of coronary heart disease, diabetes, hypertension, and a history of TIA's or previous stroke (1-5). Alcohol and drug abuse, with a variety of agents and routes of administration have also been documented as precipitating, or at least contributing, factors in the development of stroke and other cerebrovascular disorders (6-13). In the pediatric population, low birth weight/premature infants are particularly at risk for intracranial hemorrhage (6), and children with a history of arteritis (inflammation of an artery) are at risk for occlusive stroke (14, 15).

### EPIDEMIOLOGY (MASSACHUSETTS)

The annual occurrence of cerebrovascular disorders in Massachusetts was estimated from statistics derived from the Uniform Hospital Discharge Data Set (UHDDS) provided by the Massachusetts Rate Setting Commission. In TABLE 5.1, the number of discharges per year and by age group are delineated. Over the three-year period studied, 70,851 patients with cerebrovascular disorders were discharged from Massachusetts hospitals. The relative frequencies with respect to the ICD-9 codes selected for inclusion in this study are summarized in TABLE 5.2.



The incidence of cerebrovascular disorders clearly increases with age. In this study 86% of those discharged with these diagnoses were 60 years of age or older. Approximately 12% of those admitted died during their hospitalization. Males constitute 48.2% of the sample cases and females 51.8%.

TABLE 5.1

Neurovascular Disorders: Distribution of Discharges  
by  
Age and Year

<u>Age (years)</u>	<u>1984</u>	<u>1985</u>	<u>1986</u>
0 - 2	88	78	86
3 - 5	7	11	3
6 - 18	39	45	48
19 - 21	33	33	37
22 - 29	130	112	132
30 - 39	269	269	283
40 - 49	648	652	637
50 - 59	2,103	2,071	2,022
60 - 69	5,079	5,157	5,043
70 - 79	7,470	7,472	7,783
80 - 89	6,285	6,256	6,238
90 +	1,379	1,403	1,450



TABLE 5.2

Neurovascular Disorders  
Epidemiology: Massachusetts UHDDS

Diagnosis  ICD Codes	Number of Discharges		
	1984	1985	1986
Subarachnoid hemorrhage (430)	298	297	282
Intracerebral hemorrhage (431)	560	629	775
Other/Unspecified Intracerebral hemorrhage (432.0-432.9)	272	210	263
Occlusion and stenosis of precerebral arteries (433.0-433.9)	3,314	3,805	3,485
Occlusion of cerebral arteries (434.0-434.9)	3,479	4,787	7,358
Transient cerebral ischemia (435.0-435.9)	5,953	5,794	5,808
Acute, but ill-defined cerebrovascular disease (436)	5,924	4,232	2,164
Other/Ill-defined cerebrovascular disease (437.0-437.9)	3,462	3,323	3,054
Fetal/Neonatal hemorrhage (intraventricular) (772.1)	35	32	37
Fetal/Neonatal hemorrhage (Subarachnoid) (772.2)	17	14	16
Electrocution (994.8)	41	54	51

SEQUELAE

The acute consequences (sequelae) of stroke, as indicated above, include a sudden disturbance of neurological function, which is directly related to the blood vessel(s) involved and the corresponding areas of the brain which are supplied by these arteries. Altered consciousness (e.g. confusion) and drowsiness may occur, and approximately 25-30% of patients will become comatose; however, coma is more often associated with hemorrhagic events. Other acute symptoms include motor impairments (i.e. paralysis or weakness); disorders of communication (aphasia); seizures; and sensory impairments (16, 17). In some cases, the presenting symptoms may only consist of behavioral disturbance, including abrupt onset of psychosis, in the absence of sensory and motor impairment. Patients who exhibit these sudden behavioral changes, or so-called "silent strokes," can be misdiagnosed and their symptoms attributed to psychiatric disorder (18-20).

Cerebrovascular syndromes in the newborn parallel those observed in adults. Common clinical symptoms associated with cerebral hemorrhages in neonates include stupor; hemiplegia (paralysis of the right or left half of the body); abnormal pupillary responses; seizures; and coma. Hemorrhaging may also be associated with birth trauma and skull fracture. Death, if it occurs, typically results from respiratory arrest. Ischemic lesions are associated with anoxia (See section on Anoxic Brain Damage) in 90% of cases (21).

The major long-term sequelae of cerebrovascular lesions are summarized in TABLE 5.3. (17, 21, 22-30).

TABLE 5.3

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Long-term Sequelae Associated With Neurovascular Disorders

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Communication Disorder

Aphasia (Subtypes related to blood vessels involved)  
Dysarthria (Difficulties with production of speech)

Motor Impairments

Hemiplegia/Hemiparesis (paralysis or weakness)  
Facial Paralysis  
Cerebral Palsy

Sensory Impairments

Paresthesias (Burning, tingling sensations)  
Pain syndromes  
Visual Field Impairments  
Deafness  
Impairments of perception of sensory input (e.g., touch)

Cognitive Impairments

Impairment of general cognitive abilities  
Memory dysfunction  
Visuospatial deficits  
Dyspraxia (Difficulty executing learned motor commands)  
Agnosias (Disorders of recognition - faces, words, etc.)  
Impairment of executive functions (e.g., reasoning, problem-solving)  
Mental Retardation  
Dementia (associated with multiple infarcts)

Neuropsychiatric/Neurobehavioral Dysfunction

Personality change  
Post-stroke depression  
Psychosis  
Impaired psychosocial functions  
Sexual dysfunction (hyposexuality or hypersexuality)

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These impairments often lead to secondary problems, such as impaired ability to execute ADL skills independently; physical complications associated with immobility (i.e. pneumonia, muscle contractions); unemployment; and social isolation (31).

### PROGNOSIS

Neurovascular disorders represent a major cause of mortality and morbidity (impairment secondary to disease). Approximately 30% of adults who experience a stroke will die within the first 3-4 weeks after onset (17). The chance of survival is significantly reduced when coma is associated with a stroke or when this stroke is due to a hemorrhage. When coma persists for more than 48 hours, the mortality rate dramatically increases to 85-95% (16).

Patients who survive exhibit, as discussed above, a wide range of disabling conditions, and recovery of functions is dependent upon a variety of factors. Factors which appear to influence outcome, in both children and adults, include the following:

- a) age of onset
- b) type of neurovascular disorder (i.e. ischemic vs. hemorrhagic)
- c) the side of the brain which is maximally involved (i.e. left vs. right hemisphere)
- d) the nature and severity of neuropsychological, sensory, and motor impairments
- e) type of aphasia
- f) the timeliness, adequacy, and appropriateness of treatment, both medical and rehabilitative
- g) availability of a support system (16, 17, 32-42).

The variability of outcome, range of impairments, and implied service needs necessitate a continuum of care beyond the acute stage.



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## ANOXIC BRAIN DAMAGE

### DEFINITION

The human brain is highly dependent upon a constant supply of oxygen for all of its metabolic activities. Anoxic encephalopathy refers to the resultant damage that occurs when the brain is deprived of oxygen. Anoxic brain damage is the most common form of metabolic encephalopathy, which occurs in association with a variety of clinical conditions. Several etiological categories have been described, including (a) stagnant anoxia; (b) anemic anoxia; (c) histotoxic anoxia; (d) anoxic anoxia; (e) overutilization anoxia; and (f) traumatic asphyxia (suffocation). The most common of these, however, are the stagnant anoxias, while rarely observed are the anoxic anoxias, which are typically associated with, and complicated by, cardiac arrest. Secondary to the cardiac arrest, ischemia, or inadequate circulation and perfusion of blood occurs, resulting in anoxic-ischemic encephalopathy (1, 2).

### EPIDEMIOLOGY (NATIONAL)

Anoxic brain damage can occur at any age, beginning in the intrapartum (i.e. during labor and delivery) period through adulthood. Precise statistics relating to the incidence and prevalence of anoxic episodes and their associated mortality and morbidity, do not exist. The majority of studies performed have, instead, focused on clinical subpopulations, and these findings are summarized below.

In the pediatric population, perinatal asphyxia in full-term infants is a major cause of mortality and morbidity, occurring in .5% of pregnancies lasting 259 days or longer (3). However, the greatest morbidity and mortality is observed beginning at 294 days gestational age, or in the post-mature infant (3-7). The risk of perinatal asphyxia has been found to be associated with poor prenatal care, prolonged/difficult labor, opiate sedation, malpresentation (e.g. breech birth), large fetal size, mid-forceps delivery, and other obstetric complications (8, 9). Decreased mortality has been observed in response to the more frequent use of epidural anesthesia, the development and increased use of fetal monitoring, improved neonatal care, and the delivery of high risk infants by Cesarean section (8, 10).

Asphyxiation by vomitus or regurgitated food constitutes another major cause of mortality in children. An analysis of deaths from asphyxia

TABLE 5.4

## Categories of Anoxic Encephalopathy

<u>Category</u>	<u>Clinical Conditions</u>
I. Stagnant Anoxia	Cerebral arteriosclerosis Cardiac arrest Hypotension Increased intracranial pressure Congestive heart failure Myocardial infarct Peripheral circulatory failure (shock)
II. Anemic Anoxia	Carbon monoxide poisoning Abrupt loss of blood Severe anemia
III. Histotoxic (metabolic) Anoxia	Poisons (e.g., cyanide) Hypoglycemia
IV. Anoxic Anoxia	Drowning Asphyxiation Choking Anesthesia accidents Exposure to high altitudes Pulmonary disorders
V. Overutilization Anoxia	Epileptic seizures
VI. Traumatic Asphyxia	Chest Cave-in



(ICD-9 Code 911) over a ten-year period (1979-1981) in 41 states revealed a death rate of .8/100,000 between the ages of 0 to 9 years. Ninety-four percent of these deaths occurred under the age of five years, with 61% occurring under one year of age. Round, cylindrical foods have most often been implicated in these deaths, and the most common items resulting in fatalities include hot dog products, candy, nuts, and grapes (11). With respect to non-food objects or situations, entrapment in refrigerators, plastic bags, and balloons are among the more common causes of asphyxiation by choking or suffocation (ICD Code 913) in children (12). Brain damage or death associated with hypoxia or asphyxia may also occur as a result of child abuse (13, 14).

Adults may also experience asphyxiation by food, resulting in the so-called "cafe coronary." Those individuals who are intoxicated, edentulous, or wear dentures are particularly at risk (15, 16). Psychiatric patients who have been treated with dopamine blockers may also be at risk for asphyxia by choking. Among chronic psychiatric patients, those with a history of seizures, serious illness, or schizophrenia, have been demonstrated to be particularly at risk (17-20).

Approximately 30,000 people die yearly from suicide in the United States (21). Methods employed, which result in death or significant morbidity from asphyxiation or hypoxia, include drowning, hanging, overdosing, and carbon monoxide poisoning. Approximately 3,500 accidental or deliberate (suicidal) deaths from carbon monoxide poisoning occur each year in the United States (22). Mortality and morbidity from accidental causes (e.g. leaving gas appliances unlit) occurs more frequently in the elderly, while suicide and suicide attempts associated with carbon monoxide exposure are more commonly seen in the young adult age group and more frequently in males. Autoerotic asphyxiation resulting from deviant sexual practices (e.g. masturbation while in a noose) results in an estimated 500 to 1,000 unintentional deaths per year (21).

Large series studies of deaths associated with anesthesia reveal the most common cause to be "deviation from accepted medical practice" in the majority of cases. Risk factors contributing to death include low circulating blood volume (hypovolaemia), inadequate or massive blood transfusion, overdose with barbiturates, and aspiration of vomit (23). Populations at risk for hypoxic episodes or death associated with anesthesia include the elderly (24), premature infants (25), and patients who exhibit pulmonary disorders or obesity (23).

The risk of hypoxia and asphyxia has also been observed in certain occupations and recreational activities. For example, pilots and flight crew may experience anoxic episodes in response to cabin/cockpit decompression (26). Deaths among fishermen have been reported and caused by toxic concentrations of carbon monoxide, ammonia, and hydrogen sulfide released by anaerobic organisms in decaying fish (27). Traumatic asphyxia can occur in industrial situations as a result of chest trauma and concurrent closure of the airway, although a 90% survival rate has been reported (28, 29).

#### EPIDEMIOLOGY (COMMONWEALTH OF MASSACHUSETTS)

The Uniform Hospital Discharge Data Set (UHDDS) was used to estimate the incidence of anoxic encephalopathy in Massachusetts. Over the three-year period studied (1984-1986), 23,085 individuals were discharged from Massachusetts hospitals with diagnoses of anoxic brain damage or diagnoses which were presumed to reflect some degree of anoxic/hypoxic brain damage (e.g. cardiac arrest). The distribution of discharges by year and age are summarized in TABLE 5.5 below:

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TABLE 5.5

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Anoxia: Distribution of Discharges  
by  
Age and Year

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<u>Age (years)</u>	<u>1984</u>	<u>1985</u>	<u>1986</u>
0 - 2	5271	6532	7358
3 - 5	16	18	11
6 - 18	65	73	66
19 - 21	22	31	24
22 - 29	63	66	64
30 - 39	85	79	103
40 - 49	96	78	92
50 - 59	174	181	193
60 - 69	273	317	304
70 - 79	277	276	300
80 - 89	131	147	156
90 +	50	65	26

---

The death rate for the three-year period was calculated to be >33%. Approximately 45% of those discharged were female, while 55% were male. A breakdown of the number of discharges, associated with each ICD-9 code selected for inclusion in this study, is contained in TABLE 5.6.

TABLE 5.6

Epidemiology: Anoxic Brain Damage  
Massachusetts UHDDS

Diagnosis <u>ICD Codes</u>	Number of Discharges		
	<u>1984</u>	<u>1985</u>	<u>1986</u>
Anoxic Brain Damage (348.1)	242	289	242
Cardiac Arrest (427.5)	677	765	802
Complications of Administration of Anesthesia/Sedatives (Cardiac) (668.1)	9	7	8
Complications of Administration of Anesthesia/Sedatives (CNS) (668.2)	9	6	3
Intrauterine Hypoxia/Birth Asphyxia (768-768.9)	2,836	4,067	4,785
Respiratory Distress Syndrome (769)	983	984	1,102
Other respiratory problems at birth (770.8)	1,478	1,497	1,474
Toxic Effects of Carbon Monoxide (986)	83	83	100
Asphyxiation and Strangulation (994.7)	26	18	24
Complications of Surgical/Medical Care (CNS) (997.0)	181	148	157



## SEQUELAE

The sequelae (consequences) of cerebral anoxia vary in response to the etiology, duration, velocity and age of onset. In infants who have sustained perinatal asphyxia, the Post-Asphyxial Encephalopathy (PAE) or Hypoxic-Ischemic Encephalopathy (HIE) syndromes have been described. Mild PAE is evidenced in irritability, hyperalertness, mild hypotonia (depressed muscle tone) and poor sucking. Moderate PAE is associated with lethargy, seizures, and marked abnormality of muscle tone. Severe PAE typically results in coma, associated with prolonged seizures, severe hypotonia, and failure to maintain spontaneous respirations (8, 30, 31).

Long-term follow-up studies of infants who have sustained perinatal asphyxia or hypoxia reveal a continuum of handicapping conditions, which appear to be correlated with the degree of hypoxia. Those children who experience mild hypoxia of short duration may develop normally (32, 33). However, those infants who experience severe hypoxia exhibit significant physical, cognitive, and visual impairments (34, 39). The most common handicapping condition which results from severe perinatal asphyxia is cerebral palsy, which may be associated with mental retardation (34, 40).

The early onset of seizure activity, constant seizures, or a persistently abnormal EEG have been correlated with a poor outcome (10, 41). Depressed Apgar scores (See TABLE 5.7) have been utilized to ascertain the degree of asphyxia. An Apgar score of 5-7 at 1 minute indicates mild asphyxia. An Apgar of 3-4 at 1 minute indicates moderate asphyxia, while Apgars of 0-2 at 1 minute indicate severe asphyxia (42, 43). Nelson and Ellenberg found that substantial handicap occurred in 1% of survivors with low 1-minute Apgar scores; 5% of those with low 5-minute Apgar scores; and 41% of survivors with low 20-minute Apgar scores. The persistence of a low Apgar score has also been associated with increased mortality (44, 46).

TABLE 5.7

## Apgar Scoring System

	0	1	2
Heart Rate	Absent	Less than 100/min.	100/min.
Respiratory Effort	Absent	Slow, irregular	Good, crying
Muscle Tone	Limp	Some flexion of extremities	Active motion
Reflex Irritability	Absent	Grimace	Cough or sneeze
Color	Blue, pale	Body, pink Extremities, blue	Completely pink

In adults, acute neurological sequelae which result from hypoxia/anoxia include paresthesias (numbness and tingling), confusion or delirium, and speech or visual disturbances (26, 23). Neuropsychological impairments have been observed on tests of attention/concentration, perception, psychomotor ability, and most frequently memory (47). With chronic exposure, recurrent complaints of headache, vertigo, nervousness, digestive disturbances, and neuromuscular pain may be reported, in addition to depression, anxiety, and phobias (48).

In the majority of cases, in which the hypoxic/anoxic episode is transient, the symptoms described above typically resolve (26, 49,50). However, in instances where the anoxia has been severe, prolonged, or chronic, affective disorder and/or persistent impairment in the areas of memory, judgment, and psychomotor functions has been documented (6, 30, 51-53).

"Carbon monoxide psychosis" has been documented in approximately 1/500 cases of carbon monoxide poisoning. Associated neurological symptoms include hyperreflexia (increased deep tendon reflexes), incoordination and slowness of movement, Parkinsonism, and occasional paralysis. Neuropsychiatric sequelae are most often observed in patients who were comatose. It is also noteworthy that the onset of neuropsychiatric and neurological symptoms may be delayed and manifest after a period of apparent recovery (54-57).

For those patients who remain in a persistent vegetative state, the prognosis for recovery is poor (58-62).

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## NEOPLASMS

### DEFINITION

Neoplasm, or cancer, refers to an abnormal growth of tissue, or tumor. Central nervous system tumors can originate within the brain or spinal cord, and are referred to as primary. Brain tumors can also originate from cancer sites outside the CNS (e.g., ovary, lung, etc.) which metastasize, or spread, to the CNS, which serves as a secondary site.

Brain tumors may be classified as benign or malignant. Malignant tumors are resistant to treatment, invasive, and tend to recur. Brain tumors are also classified with respect to their histological composition or cell type. For example, a meningioma is a brain tumor which develops from cells within coverings of the CNS, or meninges.

### EPIDEMIOLOGY (NATIONAL)

National surveys completed by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) have demonstrated that the incidence of neoplasms of the CNS increases with age. The estimated annual incidence for primary CNS tumors was calculated to be 8.2/100,000. However, in children under the age of five years, the incidence rate is 2.5/100,000, while individuals ages 55 to 74 years exhibited an incidence rate of 20.4/100,000. For secondary tumors, the annual incidence was found to be 8.3/100,000, and males were more likely than females to exhibit these metastatic lesions. The most common primary site for males was the respiratory system, while for females, the breast was the most common primary source (1).

The most common type of primary tumor is the glioma. In children medulloblastomas (cerebellar) and astrocytomas are the most frequently observed subtypes within this histological category. Glioblastomas and meningiomas are more frequently observed among the adult population (1-6).

Neoplastic diseases of the CNS account for 90,000 deaths annually in the United States, and over 75% of these cases represent metastatic lesions associated with systemic cancer (7).

### EPIDEMIOLOGY (MASSACHUSETTS)

Over the three-year period studied (1984-1986), 12,568 Massachusetts residents with neoplastic diseases of the CNS were discharged (alive)

from Massachusetts hospitals. Of those admitted, 17.2% died during their hospitalization. In TABLE 5.8, the distribution of cases, by age and year, is summarized. Children, ages 0-18, account for only 6.2% of cases, while 49% of the discharged patients were over age 60 years. In 54% of the cases, patients exhibited primary neoplasms of the CNS; 46% represent secondary metastases. With respect to the distribution by sex, 51.4% of the cases were female and 48.6% were males.

TABLE 5.8

Neoplasms of CNS  
Distribution by Age and Year

<u>Age (years)</u>	<u>1984</u>	<u>1985</u>	<u>1986</u>
0 - 2	40	44	70
3 - 5	30	31	24
6 - 18	168	183	194
19 - 21	44	39	51
22 - 29	174	189	192
30 - 39	342	328	364
40 - 49	420	393	501
50 - 59	880	824	903
60 - 69	1,010	1,112	1,052
70 - 79	648	752	759
80 - 89	235	241	251
90 +	27	22	31

The ICD-9 Codes selected for inclusion in this survey and the relative frequencies associated with these diagnoses are summarized in TABLE 5.9 below.

TABLE 5.9			
Neoplasms of the CNS			
ICD Codes	1984	1985	1986
Malignant Neoplasm - Skull (170.0)	33	50	38
Malignant Neoplasm - Brain (191.0-191.9)	918	997	1,045
Malignant Neoplasm - Cranial Nerves (192.0)	10	14	4
Malignant Neoplasm - Meninges (192.1)	26	38	47
Malignant Neoplasm - Pituitary (194.3)	3	9	4
Malignant Neoplasm - Pineal (194.4)	22	16	14
Secondary Malignant Neoplasm -Brain (198.3)	1,849	1,877	2,052
Benign Neoplasm - Skull (213.0)	43	42	41
Benign Neoplasm - Brain (225.0)	47	59	57
Benign Neoplasm - Cranial Nerves (225.1)	103	100	78
Benign Neoplasm - Meninges (225.2)	299	313	354
Benign Neoplasm - Pituitary (227.3)	173	170	152
Benign Neoplasm - Pineal (227.4)	0	3	2
Neoplasm of Uncertain Behavior of Endocrine and Nervous System: (237.0, 237.1, 237.5, 237.7, 237.9)	319	306	336
Neoplasm, unspecified - Brain (239.6)	173	164	168



### SEQUELAE

The acute, typically focal, symptomatology associated with neoplasms of the CNS include (a) seizures; (b) headache; and (c) sensory, motor, and cognitive impairments. These symptoms are often accompanied by increased intracranial pressure, brain swelling (edema), and obstruction of the flow of cerebrospinal fluid (hydrocephalus) and vascular system. Because brain tumors represent space-occupying lesions, secondary compression or displacement (herniation) of surrounding brain tissue may occur resulting in coma, respiratory arrest, or death (8).

In some instances, psychiatric symptoms, and a conspicuous absence of significant neurological dysfunction, may be the presenting picture. Affective disorders associated with right hemisphere tumors and schizophrenia-like psychosis associated with left hemisphere tumors have been documented (9, 10).

Survivors exhibit a wide range of handicapping conditions which are directly related to the site(s) and size of the lesion and secondary compressive effects. Tumors of the cerebral hemispheres are associated with cognitive and behavioral deficits. Tumors of the posterior fossa (base of skull) are associated with hearing loss, facial paralysis, and incoordination of movement (ataxia), while tumors of the pituitary gland result in neuroendocrine dysfunction (e.g., hypothyroidism, diabetes insipidus) and visual field defects.

Dementia has been reported in adult patients with certain cerebral tumors (i.e., tumors of the corpus collosum) (11), while children who survive CNS neoplasms may subsequently exhibit learning disabilities or mental retardation (12, 13). Mental deterioration and neuroendocrine dysfunction have also resulted from treatment itself, specifically cranial irradiation, with or without chemotherapy (14, 15). These adverse (neurotoxic) effects have also been observed in patients with systemic cancer (e.g., leukemia) who undergo prophylactic CNS treatments with chemotherapy and cranial irradiation (16-17). Neurological disorders which result from systemic treatment of cancer are referred to as paraneoplastic syndromes, which may take the form of an infectious, neuromuscular, or degenerative disorder.

PROGNOSIS

Survival and functional outcome, with respect to neoplasms of the CNS, are related to a variety of factors:

- a.) Classification and histological type of tumor (e.g., benign versus malignant)
- b.) Aggressive and timely treatment
- c.) Progression of systemic disease (secondary neoplasms)
- d.) Site and size of neoplastic lesion.

As indicated above, treatment itself may be associated with, or contribute, to morbidity. In addition, many CNS neoplasms are resistant to treatment or tend to recur (18).



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## INFECTIOUS DISORDERS OF THE CENTRAL NERVOUS SYSTEM

### DEFINITION

Infectious disorders of the central nervous system largely fall into four major categories:

- 1.) Bacterial, which are caused by a variety of organisms (e.g. streptococci, staphylococci, etc.) which precipitate an inflammation of the nervous system. These bacteria enter the bloodstream and ultimately the CNS, or arise from surrounding bony cavities (e.g. nasal sinuses).
- 2.) Fungal (e.g. yeasts) which disrupt and invade the cerebrospinal fluid and vascular system.
- 3.) Parasitic which invade the central nervous system.
- 4.) Viral which are passively transferred to the CNS (host) through contaminated food, water, air, objects or through traumatic events (e.g. animal/insect bite, surgery, injury).

A brain abscess is a circumscribed (focal) collection of purulence (pus) representing another type of infectious lesion of the CNS, which can also be produced in response to a foreign object, as well as an infectious agent.

### EPIDEMIOLOGY (NATIONAL)

The incidence, mortality, and morbidity associated with infectious disorders varies with respect to the age of the individual and the specific infectious organism, and in response to the development of effective treatments (e.g. polio vaccine). Certain disorders tend to occur sporadically and/or in particular geographic regions, and some viral infections tend to incubate for years and only slowly become manifest as a degenerative disorder (see section on Progressive Disorders). For these reasons, overall incidence figures for the United States do not exist and/or remain stable. In general, however, individuals who are malnourished, immunosuppressed, or whose health is otherwise compromised are particularly at risk (3, 4). Onset in the prenatal period, when fetal defense mechanisms are in a critical developmental stage, may produce particularly devastating effects (e.g., congenital syphilis) (4).

EPIDEMIOLOGY (MASSACHUSETTS)

During the years 1984 through 1986 a total of 6,473 individuals with infectious disorders of the CNS were discharged from Massachusetts hospitals. Only 15% of cases occurred in the elderly, while young adults (ages 19-29) and children ages 0-18 years represent 59% of the cases. The distribution of cases by age and year are summarized in TABLE 5.10 below.

TABLE 5.10

Infectious Disorders of the CNS \*  
Distribution by Age and Year

<u>Age (years)</u>	<u>1984</u>	<u>1985</u>	<u>1986</u>
0 - 2	453	553	526
3 - 5	67	86	60
6 - 18	238	305	218
19 - 21	84	116	86
22 - 29	279	362	290
30 - 39	234	340	277
40 - 49	148	165	143
50 - 59	158	171	142
60 - 69	151	139	148
70 - 79	112	115	120
80 - 89	44	58	47
90 +	19	12	7
Total	1,987	2,422	2,064

\*N.B.: Cases of Acquired Immune Deficiency Syndrome are not represented in these data.



The ICD-9 codes selected for inclusion in this survey and included in the Uniform Hospital Discharge Data Set (UHDDS) are delineated in TABLE 5.11 below.

TABLE 5.11

Infectious Disorders of the CNS  
(ICD-9 Codes)

<u>Diagnosis</u>	<u>ICD Code(s)</u>
Salmonella meningitis	003.21
Amebic brain abscess	006.5
Tuberculosis of meninges and CNS	013.0-013.9
Meningococcal meningitis	036.0
Meningococcal encephalitis	036.1
Meningococcemia	036.2
Waterhouse-Friderichsen syndrome	036.3
Kern	046.0
Jakob-Creutzfeldt disease	046.1
Subacute sclerosing panencephalitis	046.2
Progressive multifocal leukoencephalopathy	046.3
Other specified slow virus of CNS	046.8
Unspecified slow virus of CNS	046.9
Meningitis due to enterovirus	047.0-047.9
Other enterovirus diseases of CNS	048
Other non-arthropod-borne viral diseases of CNS	049.0-049.9
Post-varicella encephalitis (post-chickenpox)	052.0
Herpes zoster with meningitis	053.0
Herpetic meningoencephalitis	054.3
Herpes simplex meningitis	054.72
Post-measles encephalitis	055.0
Rubella with unspec. neurologic complications	056.00
Encephalomyelitis due to rubella	056.01

TABLE 5.11

Infectious Disorders of the CNS  
(ICD-9 Codes)  
(Cont'd)

Mosquito-borne viral encephalitis	062.0-062.9
Tick-borne viral encephalitis	063.0-063.9
Viral encephalitis (other and unspecified)	064
Venezuelan equine fever	066.2
Viral hepatitis A with hepatic coma	070.0
Viral hepatitis B with hepatic coma	070.2
Other viral hepatitis with coma	070.4
Unspecified viral hepatitis with coma	070.6
Mumps meningitis	072.1
Mumps encephalitis	072.2
Juvenile neurosyphilis	090.4
Acute syphilitic meningitis	091.81
Neurosyphilis	094.0-094.9
Gonococcal meningitis	098.82
Leptospirosis meningitis	100.81
Candidal meningitis	112.83
Infection by histoplasma (meningitis)	115.01-115.91
Meningoencephalitis due to toxoplasmosis	130.0
Bacterial meningitis	320.0-320.9
Meningitis due to other organisms	321.0-321.8
Meningitis of unspecified cause	322.0-322.9
Encephalitis	323.0-323.9
Intracranial abscess	324.0
Phlebitis and thrombophlebitis (intracranial)	325
Influenza (encephalopathy)	487.8
Congenital rubella	771.0



### SEQUELAE

The acute symptoms associated with the infectious disorders include fever, headache, seizures, and altered consciousness, ranging from confusion to coma. In the progressive type (i.e. slow virus), presenting complaints may include dementia, motor dysfunction (e.g., ataxia), or personality change (5-9).

Permanent neurologic deficits can result from CNS infections in both children and adults. These include, for example, hydrocephalus, sensory loss, Parkinsonism, mental retardation, and a wide range of neuropsychological impairments (10-14).

Viral infections, in particular, (e.g., herpes encephalitis) have precipitated severe neurobehavioral dysfunction, often associated with severe memory deficits (amnesia or Korsakoff syndrome) (15). Finally, a wide range of neuropsychiatric disturbances including psychosis, depression, and schizophrenia-like disorders have been observed in patients with infectious encephalopathy (16, 17).

### PROGNOSIS

The prognosis for recovery from an infectious insult to the CNS is dependent upon several predictive factors:

- a.) The specific infectious agent
- b.) Availability and aggressiveness of appropriate treatment
- c.) Age of onset
- d.) Site and severity of the neuropathological process
- e.) The development of coma and other complications (4, 7-9).

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## PROGRESSIVE DISORDERS OF THE CNS

### DEFINITION

Progressive disorders of the central nervous system are degenerative syndromes which are typically fatal. Many progressive syndromes are inherited, while others are acquired or of unknown etiology.

### EPIDEMIOLOGY

Progressive disorders may onset during infancy through the geriatric years; however the elderly are more likely to exhibit these syndromes. The progression of the disease may be rapid or slow, and in some cases, symptoms may not become manifest for many years, subsequent to a prolonged incubation period (e.g. slow virus disorders).

The progressive disorders are associated with a wide range of neurological conditions and span all etiological categories. For a more detailed discussion of these disorders, the reader is directed to the sources listed in the references. The major syndromes and their etiological classifications are summarized in TABLES 5.12 and 5.13. Among these syndromes, the increasing number of identified persons with AIDS represents a relatively new group of individuals who are expected to exhibit progressive disorder of the CNS.

Accurate data, with respect to the annual incidence and prevalence of these specific disorders does not exist. What little information is available has largely been derived from hospital-based studies of patients who have been hospitalized, often for clarification of diagnosis. Analysis of information derived from the Uniform Hospital Discharge Data Set (UHDDS) revealed that, on the average, approximately 9,400 patients who exhibit progressive disorders are discharged from Massachusetts hospitals annually. Of those discharged, 76% were 60 years of age or older. These figures only represent an estimate of hospitalization use by patients with progressive disorders. In fact, in some cases these data may include patients with progressive disorders who were admitted more than once. Unlike with the acute disorders, the data are not representative of, or even approximations of, the annual occurrence of new cases.

### MANIFESTATIONS

Progressive disorders typically result in gradual deterioration of cognitive and physical ability. In most cases, patients will ultimately require 24-hour skilled nursing care during the end stages of these illnesses. The most common manifestations include:

TABLE 5.12

## Progressive Disorders with Onset in Childhood

<u>Classification</u>	<u>Disorders</u>	<u>Mode of Inheritance</u>	<u>Mental Retardation</u>
I. Metabolic (Lysosomal Storage Diseases)	Glycogen storage diseases Mucopolysaccharidoses Sphingolipidoses Mucopolipidoses	autosomal recessive; x-linked autosomal recessive; x-linked autosomal recessive autosomal recessive	+ + + +
II. Neuromuscular Disorders	Werdnig-Hoffmann Disease Limb-girdle Muscular Dystrophy Duchenne's Muscular Dystrophy Becker's Muscular Dystrophy	autosomal recessive autosomal recessive x-linked recessive x-linked recessive	- - - -
III. Senile-like Disorders	Progeria Cockayne Syndrome Rothmund-Thomson Syndrome	unknown autosomal recessive autosomal recessive	- + +
IV. Spinocerebellar Degeneration	Friedrich's Ataxia Ataxia-Telangiectasia Syndrome	autosomal recessive autosomal dominant autosomal recessive	- +/- +/-
V. Diseases of the Autonomic Nervous System	Riley-Day (Familial Dysautonomia)	autosomal recessive	+/-
VI. Hamartoses	Neurocutaneous Melanosis Tuberous Sclerosis Neurofibromatosis	unknown autosomal dominant autosomal dominant	+ + +/-



TABLE 5.13

## Progressive Disorders with Onset in Adulthood

<u>Classification</u>	<u>Disorders</u>
I. Infectious Disorders	Subacute Sclerosing Panencephalitis (SSPE) Progressive Multifocal Leukoencephalopathy (PML) Progressive Rubella Encephalitis Kuru Jakob-Creutzfeld Disease Gerstmann-Straussler-Scheinker Disease Acquired Immunodeficiency Syndrome (AIDS) Neurosyphilis
II. Demyelinating Disorders	Multiple Sclerosis Acute Disseminated Encephalomyelitis Acute Necrotizing Hemorrhagic Encephalitis Marchiafava-Bignami Disease
IV. Neuromuscular Disorders	Amyotrophic Lateral Sclerosis (ALS)
V. Cortical Dementias	Alzheimer Disease Pick Disease Multi-infarct Dementia
VI. Subcortical Dementias	Parkinson Disease Huntington's Disease Wilson Disease Progressive Supranuclear Palsy
VII. Neurotoxic Disorders	Alcoholic dementia Heavy metal poisoning
VIII. Metabolic Disorders	Post-anoxic dementia Combined Systems Disease



Dementia or mental retardation (childhood onset)  
Aphasia (language impairment)  
Movement disorder  
Paralysis  
Neurobehavioral dysfunction  
Inability to execute self-care

#### PROGNOSIS

The prognosis, with respect to the progressive disorders, is generally extremely poor, as there are no known cures or means of halting the course of these illnesses.

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## METABOLIC DISORDERS OF THE CNS

### DEFINITION

The term, metabolism, refers to the biochemical activities of the human body and the multiple, complex chemical pathways related to the physiological functioning of any organism. Metabolic disorders of the CNS result when these biochemical pathways are somehow disrupted. Very often, the normal sequencing of chemical reactions, which may be energy producing (catabolic) or energy-consuming (anabolic), is blocked because an enzyme, acting as a catalyst, is either diminished or absent. Enzymes, or catalysts, can speed up or slow down a chemical reaction, and when absent, may cause the abnormal or toxic accumulation of another chemical, which may ultimately affect CNS functioning. In some instances, the absence of the chemical end product of a particular pathway (e.g. hormone) which would have been normally generated may also cause indirect damage to the CNS, which is dependent upon that substance for its normal activities or growth.

Many metabolic disorders are inherited (See sections on Congenital and Progressive Disorders). Others are acquired, the most common of these being the anoxic disorders, which were discussed separately in the section on Anoxic Brain Damage.

For a comprehensive review of the metabolic disorders, the reader is referred to the resource list at the end of this section. However, the major sub-categories, which span a variety of etiologies, are summarized in TABLE 5.14.

TABLE 5.14

## Metabolic Disorders of the CNS

<u>Subcategory</u>	<u>Examples</u>
Amino Acid Disorders	Phenylketonuric (PKU) Tyrosinemia
Disorders of Lipid Metabolism	Tay-Sachs Disease Niemann-Pick Disease Gaucher's Disease
Disorders of Purine Pyrimidine Metabolism	Lesch-Nyhan Disease
Storage Diseases	Mucopolysaccharidoses Glycogen storage diseases
Neuroendocrine Disorders	Hypothyroidism
Exogenous Disorders	Malnutrition Specific vitamin deficiencies Food poisoning (e.g., botulism) Fetal Alcohol Syndrome Alcoholic dementia

MANIFESTATIONS

The metabolic disorders are associated with significant cognitive, physical, and behavioral sequelae. A large number of congenital metabolic disorders are associated with mental retardation, but, in some instances, early detection and intervention can favorably alter the intellectual outcome. For example, in 1976 a diagnostic screening test was developed for congenital hypothyroidism. Blood samples taken at the time of delivery have since been used to detect newborn infants in whom clinical symptoms of hypothyroidism are not typically evident. Treatment, i.e. replacement of thyroid hormone, is now initiated soon after screening. Prior to the development of statewide screening techniques, children with congenital hypothyroidism would gradually exhibit physical symptoms and developmental delay. Only when these symptoms became significant enough to warrant medical attention, were children eventually diagnosed and thyroid hormone therapy initiated. Although the physical manifestations of hypothyroidism (e.g. gastrointestinal disturbance, edema, etc.) would eventually resolve, the brain, which is highly dependent upon thyroid hormone, would have sustained

permanent brain damage during the period of time it was deprived of thyroid hormone. Prior to mass screening, which was initiated in the United States by the New England Hypothyroid Collaborative, based at the Massachusetts State Laboratory, children with congenital hypothyroidism exhibited varying degrees of mental impairment which was directly related to the delay in initiating hormone replacement at adequate levels. However, the early detection and initiation of treatment in children with congenital hypothyroidism has prevented mental retardation, and treated children exhibit a normal distribution of intellectual abilities. This alteration of outcome, through early diagnosis and treatment, has been observed in other congenital metabolic disorders, or "in-born errors of metabolism," as well (e.g. PKU). However, many metabolic disorders are progressive (e.g. lipid storage disorders) and/or fatal.

#### PROGNOSIS

The prognosis, with respect to the metabolic disorders, is dependent upon several factors:

- (1) Classification of the disorder
- (2) Availability of effective treatment
- (3) In some instances, early detection (prenatal or perinatal) and initiation of treatment.

In many cases, when there is no known or effective treatment, for example in the progressive types, placement in a skilled nursing, long-term care, or chronic care facility will become necessary.



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## NEUROTOXIC DISORDERS OF THE CNS

### DEFINITION

Neurotoxic substances are poisons which depress or alter the functioning of the central nervous system. Almost any poisonous substance, prescribed medication, non-prescribed medication (e.g., aspirin), or street drug taken in sufficient amounts will precipitate neurotoxicity. Other sources of exposure are environmental.

The International Classification of Diseases (ICD-9) codes 980-989 have been used to classify poisonings by drugs, medicinal, and biological substances. However, the extent to which the CNS may have been affected by exposure is not specified within these codes. Therefore, an analysis of hospital discharges via the UHDDS was not completed for the neurotoxic disorders. Some specific disorders (i.e., carbon monoxide poisoning) were discussed in previous sections (Anoxic Brain Damage), however.

Comprehensive epidemiological studies regarding the incidence, prevalence, and morbidity associated with these disorders are grossly lacking. The major and generally recognized sub-categories, are summarized in TABLE 5.15.

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TABLE 5.15

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### Subcategories of Neurotoxins

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Heavy Metals (Lead, arsenic, thallium, cadmium, iron, gold, copper, mercury)

Gases (Carbon monoxide, nitrous oxide, "nerve gas")

"Recreational" substances (Cocaine, alcohol, PCP)

Herbicides/Pesticides ("Dioxins")

Antineoplastic Agents (Vineristine, Vinblastine, Methotrexate)

Industrial Solvents (e.g., ethylene glycol)

Other medicinal substances (e.g., Vaccines)

Radiation

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## MANIFESTATIONS

The clinical manifestation, both acute and chronic, resulting from exposure to neurotoxins are specific to the agent, or toxin, and a detailed review of the symptoms associated with each is beyond the scope of this paper. A wide range of sequelae, with respect to chronic exposure, or severe and limited exposure, have been reported. These are summarized in TABLE 5.16. Toxic substances can also be carcinogenic (i.e. cancer causing) or teratogenic (i.e. causing congenital malformations).

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TABLE 5.16

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### Sequelae Associated with Neurotoxins

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#### Cognitive Impairments

Learning disabilities  
Mental Retardation  
Dementia  
Amnesic disorder

#### Sensorimotor Impairments

Peripheral nerve damage (neuropathies)  
Movement disorder  
Ataxia

#### Behavioral Impairments

Attention deficit disorder  
Affective disorder  
Psychosis  
Personality disorder

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## PROGNOSIS

The long-term sequelae associated with exposure to neurotoxins varies with respect to the neurotoxic agent, the duration of exposure, and the magnitude of the dose or level of exposure. Other factors which influence outcome, include (a) age at time of exposure; (b) accurate diagnosis or identification of the toxin; and (c) when possible, initiation of treatment and/or removal of the source. With respect to the latter, for example, individuals exposed to heavy metals can benefit from treatment with chelating agents which bind to a metal and facilitate excretion from the body. Identification and removal of the source (e.g. lead paint) can prevent further damage from occurring.

## REFERENCES

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## CONGENITAL DISORDERS OF THE CNS

### DEFINITION

Congenital literally means "born with," and the most common CNS symptom associated with these disorders is mental retardation, the severity of which relates to the specific syndrome. Some congenital disorders result from a chromosomal abnormality, and these are delineated in TABLE 5.17. Others are inherited, that is, transmitted from parent to offspring through the genes, or functional units of chromosomes. Each human cell, with the exception of the egg and sperm contain 46 chromosomes, and on each of these, there are multiple gene sites. Genes are responsible for facilitating the production of enzymes, which in turn, facilitate biochemical pathways. As was discussed in the Metabolic Disorders section, the diminished activity, or absence of a particular enzyme can cause congenital metabolic disorders (e.g., Amino Acid Disorders). Genetic disorders can be transmitted via the sex chromosomes (X or Y chromosomes) resulting in the so-called sex-linked disorders (e.g. hemophilia) or via the autosomes (i.e., chromosomes other than the sex chromosomes).

The etiology of some congenital disorders is presumed to be multifactorial. For example, the most common congenital malformation of the central nervous system, neural tube defects, or Spina Bifida, may result from a variety of interactive factors (e.g. ethnic predisposition, environmental factors, etc.). With respect to etiology, the congenital disorders can also stem from a wide range of prenatal insults, including infection (e.g. Congenital Rubella); neurotoxins (e.g. Fetal Alcohol Syndrome); vascular conditions (e.g. Sturge-Weber syndrome); or neoplastic syndromes (e.g. neurofibromatosis). For many of the congenital syndromes, however, there is no known etiology or pattern of inheritance.

### MANIFESTATIONS

For a more comprehensive review and discussion of the epidemiology and complex, often multisystem, manifestations of the congenital syndromes, the reader is referred to the sources listed in the references. The major sequelae, however, are summarized below:

Mental Retardation

Physical anomalies (abnormalities) or malformations

(e.g., skeletal, facial malformations)

Sensory impairments (hearing and vision)

Growth abnormalities (e.g., short stature)

Seizures



TABLE 5.17

## Chromosomal Disorders

Disorder	Incidence No. Cases/Newborn Population	Mental Retardation	Compromised Life Expectancy
1. Down Syndrome	1/660	+	+/-
2. Trisomy 18	.3/1000	+	+
3. Trisomy 13	1/5000	+	+
4. Trisomy 8	Rare	+	+
5. Trisomy 9	Rare	+	+
6. Trisomy 4p	Rare	+	+
7. 4p - Syndrome	Rare	+	+
8. 5p - Syndrome (Cri du Chat)	Rare	+	
9. Trisomy 9p	Rare	+	+/-
10. 9p - Syndrome	Rare	+	
11. Partial Trisomy 10q	Rare	+	+
12. 13q - Syndrome	Rare	+	
13. 18p - Syndrome	Rare	+	+/-
14. 18q - Syndrome	Rare	+/-	
15. Trisomy 20p	Rare	+	+/-
16. Cat eye Syndrome	Rare	+/-	
17. XYY Syndrome	1:840 (males only)	+/-	
18. XXY Syndrome (Klinefelter)	1:500 (males only)	+	
19. XXXY/XXXXY Syndrome	Rare (males only)	+	
20. XXXX Syndrome	Rare (females only)	+	
21. XXXXX (Penta X) Syndrome	Rare (females only)	+	
22. XO Syndrome (Turner)	1:5000 (females only)	0	+/-

p = short arm of a chromosome

q = long arm of a chromosome

Although most individuals who exhibit disorders concomitantly exhibit some degree of behavioral disturbance, in certain disorders, the presentation is particularly severe (see TABLE 5.18 below).

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TABLE 5.18

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Congenital Disorders Associated with Severe  
Behavioral Dysfunction

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<u>Disorder</u>	<u>Etiology</u>
1. 18q - Syndrome	Deletion of long arm of chromosome 18
2. XXY Syndrome	Extra Y chromosome
3. Sotos Syndrome	Unknown
4. Cornelia de Lange Syndrome	Unknown
5. Dubowitz Syndrome	Autosomal recessive
6. Lesch-Nyhan Disease	X-linked recessive
7. Prader-Willi Syndrome	Unknown; Partial deletion chromosome 15 (50%)
8. Infantile autism/ Pervasive developmental disorder	Unknown

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PROGNOSIS

The prognosis with respect to the congenital disorders specifically relates to the etiology, cognitive and physical manifestations, and the extent to which the disorder may be progressive. It can generally be assumed, however, that the vast majority of those individuals with congenital syndromes will require special education services, a continuum of additional support services, and case management throughout their lifetimes. Frequent re-evaluation and medical follow-up can also be anticipated for most, and for those who exhibit severe medical problems or progressive conditions, placement in a skilled nursing or long-term care facility will frequently and ultimately be necessary. For those who exhibit severe behavioral dysfunction, placement in residential treatment programs is often indicated.

In some cases, prevention of new cases can be achieved through screening of suspected carriers (i.e. parents), prenatal testing of the fetus (e.g. amniocentesis), or genetic counseling.

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## Chapter VI





## SUMMARY OF MAJOR FINDINGS



## MAJOR FINDINGS

### Epidemiology

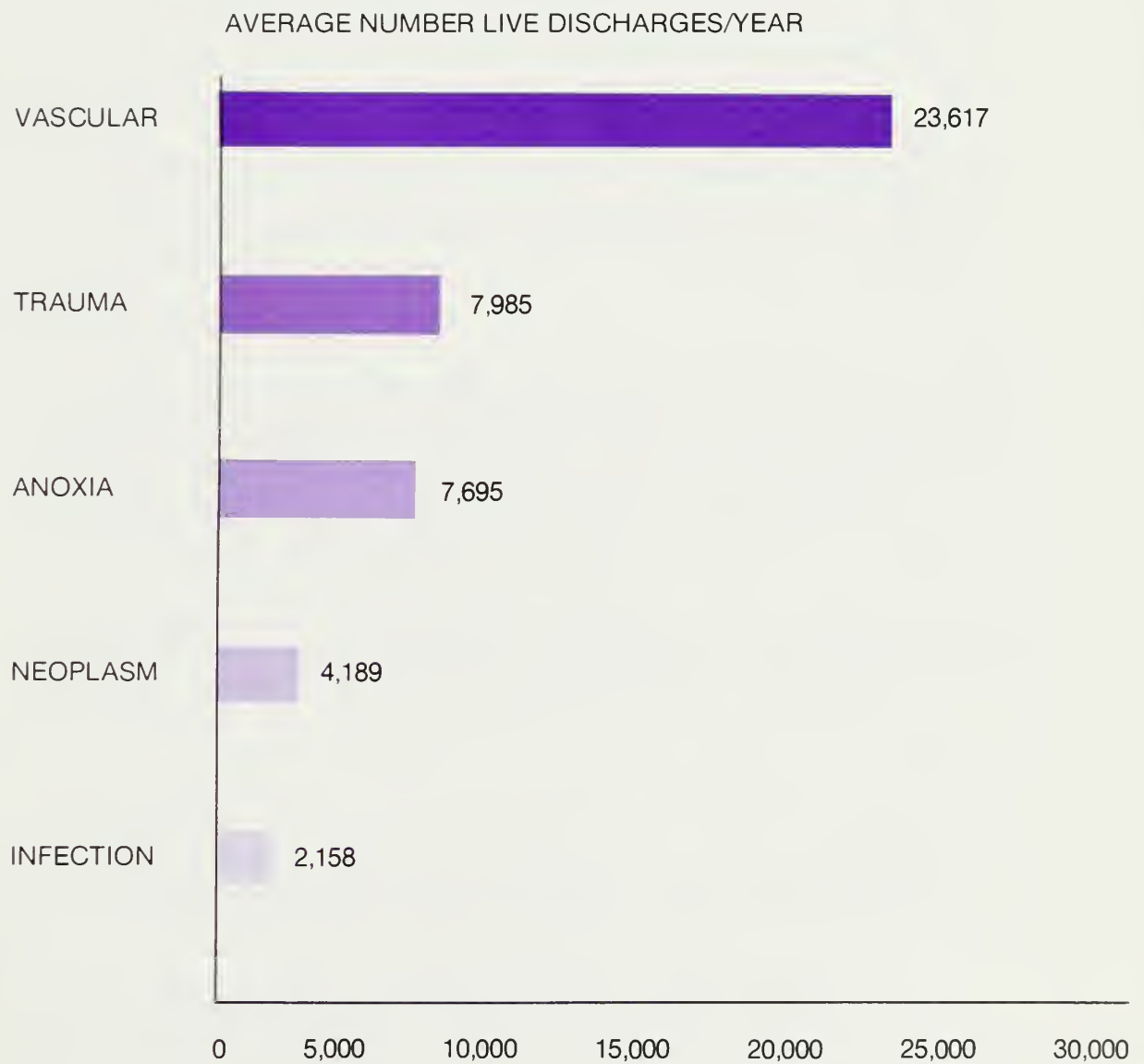
1. Each year over 46,000 Massachusetts residents are discharged from Massachusetts hospitals with acquired brain injury (see TABLE 6.1). These disorders result from infections, traumatic, vascular, neoplastic, and anoxic insults to the central nervous system. Figures presented in this report exclude any persons with congenital, progressive (degenerative) and neurotoxic syndromes, as well as those individuals who exhibit organic brain syndromes which do not necessitate hospitalization, thereby underestimating the scope and incidence of these disorders.
2. Acquired brain damage can be sustained at any age, with onset occurring in the perinatal period through the geriatric years, for all major categories.
3. The leading cause of acquired brain damage in Massachusetts is stroke, with eight-six percent of these cases occurring among the elderly ( $\geq 60$  years of age).
4. The second leading, non-progressive cause of acquired brain damage is traumatic brain injury (TBI), with an average of 7,985 cases being discharged from Massachusetts hospitals each year. There was a 3.9% death rate across the three year period studied. The majority (61%) of those discharged are children or young adults. Average acute care costs, with respect to this disorder, amount to over \$45 million/year.
5. The most commonly observed neurological disorder in childhood is anoxic brain damage, with 83 percent of cases occurring in children of pre-school age. The highest mortality ( $> 33\%$ ) is also associated with this category.
6. The majority of congenital disorders of the CNS are associated with mental retardation.
7. The sequelae, or consequences, of acquired brain injury are similar regardless of the etiology. That is, all acquired encephalopathies are associated with cognitive, behavioral, physical, vocational, and psychosocial impairments which necessitate a continuum of services, beyond acute care.



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**TABLE 6.1**  
**Acquired Brain Injuries**  
**(Massachusetts)**

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8. A small percentage of those who sustain acquired brain injuries will require specialized programs, including:

- a) chronic skilled nursing care
- b) coma management
- c) neurobehavioral/neuropsychiatric treatment

Specialized units for those with progressive disorders may also be anticipated.

9. For many of the acquired brain syndromes, the development and implementation of aggressive prevention programs would appear to be indicated. Prevention programs could potentially and significantly reduce mortality and morbidity, with respect to these disorders.

#### Needs Assessment

1. Data derived from the Statewide Head Injury Program (SHIP) Needs Assessment-revealed that the leading cause of head injury is motor vehicle-related accidents, while falls are the next most common cause. Of those involved in motor vehicle accidents, less than 20% were wearing their seat belts and more than 50% indicated they had used drugs or alcohol within the 24 hour period prior to their injury.
2. Clients referred to SHIP are more likely to have sustained severe head injuries, require community reintegration services, and be dependent on public assistance programs (e.g., Medicaid, Medicare).
3. A small percentage of head injury survivors exhibit blindness and hearing loss.
4. A sub-group of the head injured population will require total care for the remainder of their lives. This group includes individuals who do not regain consciousness.
5. A small percentage of individuals will develop severe neurobehavioral dysfunction evidenced in assaultive and self-injurious behavior.

6. People with head injuries are at high risk for depression which may be associated with a suicide attempt.
7. Head-injured individuals are at risk for developing substance abuse problems and engaging in criminal activity.
8. The data support that individuals with traumatic head injuries have serious difficulty returning to work or becoming employed after their injury and this is more likely to be experienced by those who have sustained severe injuries.
9. The majority of adults who are traumatically head-injured live at home with their families.
10. Consumers, families and professionals indicate that major service gaps exist within the continuum of care for head-injured people in Massachusetts, particularly with respect to community reintegration services.

#### IDENTIFIED NEEDS AND PRESENT SERVICES

##### Case Management

Case management services are an integral part of the comprehensive system of care for people with head injuries. The recovery process that leads to reintegration will undoubtedly include multiple services, care givers and funding sources. The model of case management developed by SHIP proposes that effective case management can only be accomplished through the appropriate and timely identification, mobilization and coordination of services. The intensity and complexity associated with this approach calls for a case manager: client ratio of 1:20. SHIP regulations state that all eligible clients will receive these case management services (107 CMR 73.01).

As of 12/31/88 there were over 700 referrals to SHIP with an average of 20 new referrals being made each month. These numbers grossly under represent the need for services statewide when you compare them with the total number of people discharged annually from Massachusetts hospitals with diagnoses of traumatic brain injury.

The total staff positions allocated to SHIP as of the end of this fiscal year will allow the program to provide effective case management to approximately 180 head-injured survivors or almost a third of the present SHIP population. However, this service continues to be a need of the remaining eligible applicants.

### Continuum of Care

While Massachusetts hospitals provide comprehensive acute care and rehabilitation programs, the majority of services outlined under the previous Chapter (Stages of Recovery: Client Pathways) do not presently exist within the Commonwealth or may be inaccessible to head-injured people due to their lack of adequate financial resources. SHIP has taken the lead in initiating efforts that begin to address these issues primarily through the facilitation and implementation of program development activities throughout the state.

This sub-section will identify areas of need and outline what the state, via its various human service agencies, particularly SHIP, has done to improve accessibility for individuals with head injuries and their families.

1. It is noteworthy that although several extended rehabilitation and coma care programs have been developed in long-term care facilities in Massachusetts, they are not generally accessible to individuals who rely on public assistance, i.e., Medicaid. To this end, SHIP and the Department of Public Health convened an interdisciplinary task force that developed draft supplemental standards to be used to pilot specialized units in long-term care facilities for brain injured people that would be accessible to Medicaid recipients under a new reimbursement rate (to be submitted to E.O.H.S. later this year). The state would be in a better position to respond to the results of the potential pilot projects and ongoing Determination of Need (DON) applications for increased SNF licensed beds for the brain-injured population if the following questions could be answered:
  - ° Whether there is a need to develop these services
  - ° Whether this need is relevant to Massachusetts residents
  - ° Whether the services are available but, again, inaccessible to Massachusetts Medicaid recipients due to the relatively low reimbursement rate as compared to the actual cost of services and the rates provided by other bordering New England states.
  - ° Whether these beds are currently available in our public health hospitals.



2. Over the past two years, it has frequently been necessary for SHIP to transfer clients to out-of-state facilities in an effort to meet individual needs, particularly for those head injured survivors with severe behavioral dysfunction. These post-acute programs are not only costly (average annual charge of \$150,000 per client) but separate an individual from their family and support network. To address this problem SHIP has awarded a contract to McLean Hospital to develop a 12 bed inpatient neurobehavioral unit. Given the prevalence of neurobehavioral disorder associated with traumatic brain injury in children and adults and the estimated length of stay dictated by the severity of the disorder and treatment, this unit will not have the capacity to serve the total needs of the state. It is anticipated, however, that this innovative treatment model will develop the necessary clinical and administrative guidelines and standards that will allow for its replication at a later date.

This specialized unit will focus on rehabilitation and assist head-injured individuals to gain the controls necessary to move on to a less restrictive environment. This can only be effective if transitional programs are made available beyond the neurobehavioral unit providing gradual movement toward community integration. Consideration must be given for this next step in the continuum in order to avoid a shift within the unit from rehabilitation to custodial care.

3. The majority of unmet needs within the continuum of care identified by head-injured people, families and professionals cover a broad range of community reintegration services. The greatest service gaps exist in the following categories:
  - a. Day program services that exist in the Commonwealth are primarily targeted for a mentally retarded or mentally ill population. People with head injuries are in need of programs that can provide them with a peer group they will accept and interact with, as well as specialized intervention strategies geared to their individualized needs. SHIP has developed, to date, two regionally based day programs in Western and Central Massachusetts. A competitive bid process has been initiated this fiscal year and will result in the award of two contracts to develop similar programs in the Northeastern and Southeastern regions of the state. Given the success of these programs and the numbers of traumatically head-injured individuals who could benefit, there continues to be a need to develop these services for this population.



- b. Traditional Vocational Rehabilitation provides vocational training via utilization of established post-secondary educational institutions, vocational trade schools or sheltered workshops that are primarily designed to serve the mentally retarded or mentally ill populations. The majority of brain injured clients cannot successfully be integrated into any of these settings.

The Massachusetts Rehabilitation Commission's Vocational Rehabilitation Division has created the only innovative model of supported work specifically developed for individuals with brain injuries. It does not, however, address the long-term support needs necessary for a number of head injury survivors to successfully re-enter the competitive work place. Therefore SHIP is initiating the development of a multi-year supported employment model project that will provide replication materials and a technical assistance capacity for other potential vendors. Further statewide development and expansion of both the supported work and supported employment models needs to occur given the percentage of people with head injuries who have not been able to return to work.

- c. Supervised housing programs in the Commonwealth for handicapped people have again primarily been developed to serve discrete populations such as the mentally retarded, mentally ill or physically handicapped. These programs are not clinically appropriate to serve a head injured clientele, nor do they provide an appropriate peer group. A very high percentage of head injured adults are living at home with family members. SHIP recognizes the enormous gap that exists in residential services for this population. To this end, SHIP has developed a staffed apartment serving two head-injured women and has begun to plan for another community residence for four male head injury survivors with substance abuse problems. In addition, an RFP will be issued in the Spring to address the needs of three more at risk individuals. Continued and expanded efforts in this area are critical to individuals with traumatic head injury and their families.

- d. Many family members of individuals with a traumatic head injury who are without services have had to accept the responsibility of providing constant supervision to that individual. Sometimes this has resulted in isolation, reduced income to the family, and the client's dependency on parents beyond the normal developmental period. The stresses that result within the family unit over long periods of time sometimes result in crisis situations.

The Commonwealth presently provides respite care for children and adults through a number of agencies. These respite care services and dollars, are accessible to only a small number of head-injured people, primarily children. Adults often do not meet the eligibility criteria set forth in these agency's regulations or the respite programs are clinically inappropriate. There is a need for a service delivery system to provide respite services to these families in an effort to maintain a more stable living situation until alternatives can be developed.

- e. Isolation of head injury survivors is a critical issue facing those individuals who are living at home, receiving no services and who have little opportunity to interact with anyone beyond their family members. The ability to go out in the community and relate to peers in a structured social situation can not be underestimated when looking at cost-effective strategies that may reduce individual and family stress, contribute to the stabilization of a family unit and provide meaningful activity for the traumatically head-injured individual. Existing leisure and recreation programs, again, are geared toward other disability groups. There is a need for a statewide network of leisure/recreation services for individuals with head injuries.
- f. Many people with head injuries are unable to drive or use public transportation because of cognitive, medical and/or physical impairments. The cost of private transportation (i.e., cabs) is extremely high. Presently, transportation can only be reimbursed if it falls within one of the following areas:
  - ° transportation to a medically prescribed service such as physical therapy - paid for by Medicaid

- ° transportation to attend a D.M.R. licensed day program  
- paid for by D.M.R. if eligible D.M.R. client
- ° transportation to a vocational rehabilitation training  
program - paid for with Vocational Rehabilitation  
funds.

Head injury survivors need transportation to specialized day programs that are not licensed by D.M.R.; competitive employment sites obtained independently or through supported work or supported employment programs; leisure and recreation programs; and psychotherapy appointments. Existing transportation reimbursement sources do not cover these areas which, if accessible, would encourage and support community re-integration.

### Special Education Services

Given the number of children who sustain traumatic brain injuries a need exists for a continuum of special education services that are targeted to address the impact this disability has upon these childrens' educational growth. As with the adult population, a percentage of these children will develop severe neurobehavioral dysfunction making them unmanageable in traditional or existing educational settings. Over the past two years SHIP has been assigned fiscal responsibility for five such children who were placed in out-of-state facilities. The total cost of these services has been approximately one million dollars per year.

There is a need for residential educational programs within Massachusetts that are 766 approved and can accommodate the special needs of this sub-population.

### Crisis Intervention Strategies

SHIP does not have the capacity to respond to head injury clients in the event of an acute psychiatric crisis (i.e., suicidal, homicidal or severely assaultive behavior). Department of Mental Health screening clinics appear to be in a better position to evaluate and transfer these clients to appropriate hospital-based treatment programs. This service has been tapped on several occasions, where cooperative efforts between SHIP and DMH screening clinics have facilitated hospitalization of at risk clients, when indicated. People with head injuries need to continue to have access to this system in the event no other resources exist.



### Creative Utilization of Other Fiscal Resources

SHIP's mandate is to meet the needs of traumatically head-injured people and their families through the coordination and development of a service delivery system that is both accessible and cost effective. To this end, SHIP must look to the creative utilization of all available resources.

1. The majority of SHIP clients are more than 3 years post-injury. Research regarding TBI recovery suggests that the most substantial gains and benefit from intensive rehabilitation occurs within 2 years of the injury itself. Therefore, the greatest area of programmatic need for the SHIP population is in the post-acute stage. Reintegration services for these head injury survivors must be available to meet these needs. Program options should include community-based housing, day and ancillary support services. A major consideration in the development of these services is the cost associated with the varying levels of staffing/supervision required by those survivors with more severe head injuries. Given that a significant number of these SHIP clients are medicaid recipients, Title XIX can not be overlooked as a possible resource for reimbursement of personal care services in the community in the future.
2. Head-injured individuals with less severe cognitive impairments appear to be at risk for developing neuropsychiatric disorders such as depression, organic mood syndrome, and at times, suicidal behavior. Active substance abuse is not an uncommon concomitant feature. Generally, the development of psychiatric morbidity can be attributed to the head-injured person's perceived losses and difficulties in coping with the changes in their ability to function independently, work, and participate in social activities.

Psychotherapeutic services for TBI individuals and their families need to be provided by professionals who have training and expertise in the area of therapy, as well as an understanding of the cognitive impairments associated with brain injury. Clinicians trained with this combination of knowledge and skills are neuropsychiatrists and neuropsychologists. There are a limited number of neuropsychiatrists in Massachusetts who offer psychotherapeutic services. Therefore, there is a need to expand access to these services through the clinical expertise of neuropsychologists. However, neuropsychologists are not

presently able to receive reimbursement under Medicaid for psychotherapeutic intervention. This presents a serious problem of accessibility given the numbers of people with head injuries who are dependent on the Medicaid program. Treatment for these psychological problems is critical in order to reduce acute psychiatric crisis and the demands on Massachusetts state hospitals.

3. SHIP's regulations state that case management will be provided to all eligible clients. SHIP will be providing these services to 180 people by the end of this fiscal year, however, the waiting list of eligible clients continues to grow. Increases in staffing will be necessary if this need is ever to be met. Recent federal legislation enables the state to claim reimbursement for case management services for Title XIX eligible individuals. This may be an avenue for revenue that has previously been unexplored.
4. The extensive and often life-long service needs of individuals with brain injury can be a financial burden on the individual and their family as well as the state. Given the incidence of traumatic brain injury annually in the Commonwealth, the state must look to creative methods of tapping other potential financial resources. The reimbursement of non-medical and long-term care services needs to be explored through the private insurance industry.

#### Identification and Initiation of Injury Prevention Strategies

Given the number of traumatically brain injured individuals discharged from hospitals each year and the extent of rehabilitation services and long-term care many will require, there is a need to seriously explore prevention strategies that will reduce the risk of injury to residents of this state. The four leading causes of head injury are motor vehicle related accidents, falls, sporting accidents and assaults. Each requires somewhat different injury prevention strategies cutting across three strategic areas - environmental change, legislative action and education. This issue must be addressed in a cohesive fashion. A central point within the state would provide the leadership and coordination necessary to accomplish this task.



### Care, Cooperation and Coordination

Individuals with traumatic brain injury often present with a number of disorders and impairments requiring specialized services. The following agencies within the Executive Office of Human Services have the knowledge, expertise and, at times, programs necessary to address these needs through cooperative activities. Each agency listed must be an integral part of any planning efforts that are initiated. Coordination can only be accomplished through the development of written policies and guidelines that clarify each agency's responsibilities with this population. These agencies need to work together to implement this effort.

- Department of Mental Health
- Department of Mental Retardation
- Department of Public Health -
  - Hospital Division
  - Alcohol and Substance Abuse Division
- Department of Public Welfare -
  - Medicaid Division
- Massachusetts Commission for the Blind
- Massachusetts Commission for the Deaf and Hard of Hearing
- Massachusetts Rehabilitation Commission -
  - Vocational Rehabilitation Division
  - Independent Living Division
- Department of Corrections
- Parole Board
- Office for Children

Other Departments, Commissions and Secretariats critical to the development of policies and procedures regarding this population are:

- Department of Education
  - Special Education Division
- Executive Office of Elder Affairs
- Office of the Commissioner of Probation

# Appendices



## APPENDIX A





NEEDS ASSESSMENT OF THE HEAD INJURED

MASSACHUSETTS REHABILITATION COMMISSION  
STATEWIDE HEAD INJURY PROGRAM

AND

THE CENTER FOR SURVEY RESEARCH  
UNIVERSITY OF MASSACHUSETTS-BOSTON

Confidential: Information collected through this survey will not be used in any way which will identify individual persons.

## INSTRUCTIONS

### WHO SHOULD FILL OUT THE SURVEY?

Either the head injured person themselves, if they are able, or their legal guardian, or another family member or friend who knows the head injured person's situation very well.

The questionnaire is phrased as if it is being filled out by a guardian or family member because the reality is that many head injured persons will not be able to fill out the questionnaire by themselves. If you are the head injured person, and are able to fill out the survey, we hope you will understand this formatting decision.

If the person who should fill out this questionnaire lives elsewhere, we hope you will get it to them as soon as possible. It is important that the survey be completed and returned very soon.

### HOW SHOULD THE SURVEY BE COMPLETED?

Answer each question or subpart of a question, unless the instructions tell you to skip over a few questions.

Unless otherwise indicated, pick only one answer for each question or part of a question, that best reflects the head injured person's situation.

Indicate your answer by checking the box like this:

1[☒] Yes

2[ ☐ ] No

### WHAT DO I DO WHEN I'M FINISHED?

Place the questionnaire and your signed consent form in the enclosed postage paid envelope and mail it to the Center for Survey Research. We pledge that no information you provide us will be used in any way which identifies you as an individual.

In order to adequately represent your situation and experiences in the data that will help generate a report to the State legislature, it is important that we receive your completed questionnaire as soon as possible.

If you have any questions about filling out the questionnaire or the report that will be produced, you can call Debra Kamen at the Massachusetts Statewide Head Injury Program (617-727-8732) or Tom Mangione at the Center for Survey Research (617-956-1150).

A. Background

A1. What is the present age of the head injured person?

— — YEARS OLD

A2. What is the current living situation of the head injured person?

1 ☐ Home or  
apartment

2 ☐ Hospital

3 ☐ Other type  
of facility

A3a. Who is the head  
injured person  
living with?

1 ☐ Living alone

2 ☐ With Family

3 ☐ With  
Nonrelatives

A3b. What type of  
hospital?

1 ☐ An acute care  
hospital

2 ☐ A chronic care  
hospital

3 ☐ A psychiatric  
hospital

4 ☐ A rehabilitation  
hospital

A4b. What is the name  
of the hospital?  
\_\_\_\_\_

A3c. What type of  
facility?

1 ☐ A community residence  
with supervisory staff

2 ☐ Transitional housing

3 ☐ Prison or jail

4 ☐ A nursing home or  
other long term care  
facility

A4c. What is the name  
of the facility?  
\_\_\_\_\_

A5. What is the head injured person's current marital status?

1 ☐ Married

2 ☐ Separated

3 ☐ Divorced

4 ☐ Widowed

5 ☐ Never Married

A6. Who is the legal guardian for the head injured person?

1 ☐ Guardian for himself/herself

2 ☐ Parents

3 ☐ Someone else (please specify relationship to head injured person):  
\_\_\_\_\_

A7. Is the head injured person a veteran?

1 ☐ Yes      2 ☐ No

A8. Is the head injured person currently working at a job?

1 ☐ Yes

2 ☐ No

A9a. What type of work?

1 ☐ Full time-paid

2 ☐ Part time-paid  
(less than 35  
hours per week)

3 ☐ Works in a  
supported or  
supervised work  
program

4 ☐ Does volunteer work

A9b. Has the head injured person worked  
at a job since he/she was injured?

1 ☐ Yes      2 ☐ No

A10b. Does the head injured person plan  
to be employed in the future?

1 ☐ Yes      2 ☐ No

All. Prior to the injury what was the head injured person's employment status?

1 ☐ Employed full time

2 ☐ Employed part time

3 ☐ Working in a supported or supervised work program

4 ☐ Doing volunteer work

5 ☐ Unemployed and in school

6 ☐ Unemployed and not in school

7 ☐ Homemaker

8 ☐ Retired

A12. Is the head injured person currently attending school?

1 ☐ No

2 ☐ Attending elementary school

3 ☐ Attending junior high school or a middle school

4 ☐ Attending high school

5 ☐ Attending college

A13. Is the head injured person currently attending a vocational training program?

1 ☐ Yes                      2 ☐ No

A14. What is the highest level of education that the head injured person has completed?

1 ☐ Grade school

2 ☐ Some high school

3 ☐ High school diploma or GED (General Education Degree)

4 ☐ 2 yr college degree (Associates Degree)

5 ☐ 4 yr college degree

6 ☐ A Master's, PhD, or Professional Degree

A15. While in elementary school or high school did the head injured person receive any special education services?

1 ☐ Yes

2 ☐ No

A16. While in elementary school or high school was the head injured person ever suspended or expelled from school?

1 ☐ Yes

2 ☐ No

B. Information About the Injury

B1. What caused the head injury?

01 ☐ Accident while driving a motor vehicle

02 ☐ Accident while a passenger in a motor vehicle

03 ☐ Hit by a motor vehicle while a pedestrian

04 ☐ Motorcycle accident

05 ☐ Bicycle or moped accident

06 ☐ Boating accident

07 ☐ Sports accident

08 ☐ Work accident

09 ☐ Suicide attempt

10 ☐ Attacked by someone

11 ☐ Fall

12 ☐ Other (please specify:) \_\_\_\_\_

B2. Was the head injured person wearing a seat belt?

1 ☐ Yes

2 ☐ No



B3. What was the date of the head injury?

Month      Day      Year

B4. In what town and state did the injury happen? (Record the nearest town if the accident happened on the highway.)

Town      State

B5. Did the head injured person drink any alcohol or take any drugs during the 24 hour period before the injury?

1 ☐ Yes      2 ☐ No      3 ☐ You don't know

B6. When the person received the head injury, how long did he/she lose consciousness?

- 1 ☐ There was NO loss of consciousness  
2 ☐ A BRIEF (less than 1 hour) loss of consciousness  
3 ☐ A loss of consciousness for 1 to 24 hours  
4 ☐ A loss of consciousness for greater than 24 hours but he/she regained consciousness  
5 ☐ A loss of consciousness for greater than 24 hours and he/she has not regained consciousness yet  
6 ☐ There was loss of consciousness but you are uncertain for how long  
7 ☐ You don't know

B7. Was the head injured person hospitalized for treatment?

- 1 ☐ No hospital treatment at all (SKIP TO B11)  
2 ☐ Only seen in the emergency room and then released  
3 ☐ Admitted to hospital at least for one night

B8. After the head injured person was released from the hospital that they were first treated at, did he/she receive any out-patient rehabilitation services from that hospital?

1 ☐ Yes      2 ☐ No

B9. Was the head injured person transferred to a rehabilitation hospital after being released from the first hospital that gave treatment?

1 ☐ Yes      2 ☐ No

B10. Was the head injured person transferred to a nursing home or other long-term care facility after being released from the hospital(s) where he/she was provided treatment?

1 ☐ Yes      2 ☐ No

11. Which of the following financial benefits does the head injured person currently receive or qualify for.

- |  |           |          |               |
|--|-----------|----------|---------------|
| a. Has his/her own private medical insurance                       | 1 [ ] Yes | 2 [ ] No |               |
| b. Is covered by your medical insurance                            | 1 [ ] Yes | 2 [ ] No |               |
| c. Has received a financial settlement because of the injury       | 1 [ ] Yes | 2 [ ] No | 3 [ ] Pending |
| d. Receives Medicaid   | 1 [ ] Yes | 2 [ ] No |               |
| e. Receives Social Security Insurance (SSI)                        | 1 [ ] Yes | 2 [ ] No |               |
| f. Receives Social Security Disability Insurance (SSDI)            | 1 [ ] Yes | 2 [ ] No |               |
| g. Has Medicare  | 1 [ ] Yes | 2 [ ] No |               |
| h. Receives worker's compensation                                  | 1 [ ] Yes | 2 [ ] No |               |
| i. Receives payments from his/her own private disability insurance | 1 [ ] Yes | 2 [ ] No |               |

### C. Medical History

11. We would like to know about the head injured person's medical history both before and after the injury occurred. Please check the "Before" box if the condition was experienced before he/she received the head injury and check the "After" box if the condition was experienced after the head injury. Check both boxes if he/she experienced this condition both before and after the head injury.

- |                            |                     |                    |
|----------------------------|---------------------|--------------------|
| a. Pre-natal Complications | 1 [ ] Before Injury |                    |
| b. Delivery Complications  | 1 [ ] Before Injury |                    |
| c. Birth Defect            | 1 [ ] Before Injury |                    |
| d. Developmental Problems  | 1 [ ] Before Injury |                    |
| e. Mental Retardation      | 1 [ ] Before Injury |                    |
| f. Learning Disabilities   | 1 [ ] Before Injury | 1 [ ] After Injury |
| g. Behavioral Disorders    | 1 [ ] Before Injury | 1 [ ] After Injury |
| h. Psychiatric Disorder    | 1 [ ] Before Injury | 1 [ ] After Injury |
| i. Depression              | 1 [ ] Before Injury | 1 [ ] After Injury |
| j. Suicide attempt         | 1 [ ] Before Injury | 1 [ ] After Injury |

k. Alcohol Abuse	1 [ ] Before Injury	1 [ ] After Injury
l. Drug Abuse	1 [ ] Before Injury	1 [ ] After Injury
m. Criminal Record	1 [ ] Before Injury	1 [ ] After Injury
n. Endocrine Disorder (thyroid, pancreas, pituitary)	1 [ ] Before Injury	1 [ ] After Injury
o. Hypertension (high blood pressure)	1 [ ] Before Injury	1 [ ] After Injury
p. Cancer	1 [ ] Before Injury	1 [ ] After Injury
q. Heart condition	1 [ ] Before Injury	1 [ ] After Injury
r. Cerebrovascular Disorder (Stroke)	1 [ ] Before Injury	1 [ ] After Injury
s. Lung Disorder	1 [ ] Before Injury	1 [ ] After Injury
t. Seizures	1 [ ] Before Injury	1 [ ] After Injury
u. Infections of Brain (Meningitis, Encephalitis)	1 [ ] Before Injury	1 [ ] After Injury
v. Another head injury	1 [ ] Before Injury	1 [ ] After Injury
w. Episodes of loss of consciousness	1 [ ] Before Injury	1 [ ] After Injury
x. Surgeries	1 [ ] Before Injury	1 [ ] After Injury
y. Hospitalizations	1 [ ] Before Injury	1 [ ] After Injury
z. Visual disorders	1 [ ] Before Injury	1 [ ] After Injury
aa. Hearing disorders	1 [ ] Before Injury	1 [ ] After Injury
bb. Language disorders	1 [ ] Before Injury	1 [ ] After Injury
cc. Physical handicaps	1 [ ] Before Injury	1 [ ] After Injury
dd. Pain Syndrome	1 [ ] Before Injury	1 [ ] After Injury

D. Functional Status

In this section of questions we want to find out how the head injured person functions in day to day areas of life.

D1. For each of the activities listed below indicate whether the head injured person cannot perform them at all, or can perform them but needs some assistance or supervision from someone else, or can perform them by himself/herself without any help.

- |  |                      |                          |                      |
|--|----------------------|--------------------------|----------------------|
| a. Feeding   | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| b. Dressing  | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| c. Bathing   | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| d. Toileting   | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| e. Budgeting/banking   | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| f. Contact police or fire department in an emergency         | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| g. Contact a doctor when ill                                 | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| h. Can take responsibility for taking prescribed medications | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| i. Can use household appliances                              | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |
| j. Can take public transportation                            | 1 [ ] Cannot Perform | 2 [ ] Performs With Help | 3 [ ] Performs Alone |

D2. Please indicate the head injured person's ability to move about.

- 1 [ ] Not able to walk and cannot use a wheelchair
- 2 [ ] Not able to walk but can use a wheelchair
- 3 [ ] Can walk with mechanical assistance but cannot climb stairs
- 4 [ ] Can walk with mechanical assistance and can climb stairs
- 5 [ ] Can walk without mechanical assistance but cannot climb stairs
- 6 [ ] Can walk without mechanical assistance and can climb stairs



D3. What is the head injured person's ability to communicate?

- 1 ☐ Can talk and can be understood easily
- 2 ☐ Can talk but is difficult to understand
- 3 ☐ Cannot talk but uses a communication device effectively
- 4 ☐ Cannot talk and does not use a communication device effectively

D4. What is the head injured person's ability to see?

- 1 ☐ Has no visual problems
- 2 ☐ Has impaired vision
- 3 ☐ Is blind in both eyes

D5. What is the head injured person's ability to hear?

- 1 ☐ Has no hearing problems
- 2 ☐ Has impaired hearing
- 3 ☐ Is deaf in both ears

D6. Can the head injured person move himself/herself 100 feet in 2 minutes without verbal or physical help from anyone including getting into a wheelchair or getting and using a mechanical device to aid with walking if needed?

- 1 ☐ Yes
- 2 ☐ No

D7. Can the head injured person find his/her way and not get lost in familiar settings without any help from anyone?

- 1 ☐ Yes
- 2 ☐ No

D8. Is the head injured person aware of hazardous situations or obstacles and can he/she avoid them without verbal or physical help from anyone?

- 1 ☐ Yes
- 2 ☐ No

D9. If the head injured person would need to carry out some action quickly in response to a particular situation, could he/she begin and continue this action without verbal or physical help from anyone?

- 1 ☐ Yes
- 2 ☐ No

D10. Can the head injured person solve problems in such a way that if one solution doesn't work he/she can think of another solution?

- 1 ☐ Yes
- 2 ☐ No



D11. Can the head injured person learn, remember, and follow simple directions about safety and emergency procedures?

1 ☐ Yes                      2 ☐ No

D12. If the head injured person was in a hospital or treatment facility, could he/she go to scheduled treatment sessions by themselves?

1 ☐ Yes                      2 ☐ No

D13. What is the maximum amount of time the head injured person can work without supervision on a task or project or work assignment?

1 ☐ less than 15 minutes

2 ☐ 15 to 30 minutes

3 ☐ 30 to 45 minutes

4 ☐ 45 to 60 minutes

5 ☐ More than one hour (specifiy maximum number of hours: ) \_\_\_\_\_

D14. What is the maximum amount of time the head injured person can work with supervision on a task or project or work assignment?

1 ☐ less than 15 minutes

2 ☐ 15 to 30 minutes

3 ☐ 30 to 45 minutes

4 ☐ 45 to 60 minutes

5 ☐ More than one hour (specifiy maximum number of hours: ) \_\_\_\_\_

D15. This next question lists a variety of behaviors and thinking problems. We'd like you to tell us to what extent they are problems for the head injured person?

	Never a Problem	Rarely a Problem	Sometimes a Problem	Often a Problem	Very Often a Problem
a. Threatens to injure others	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
b. Assaults others physically	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
c. Threatens to destroy property	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
d. Destroys property	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
e. Threatens to injure self	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
f. Injures himself/herself purposely	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
g. Currently abuses alcohol	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
h. Currently abuses drugs	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
i. Touches or molests others sexually	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
j. Exposes self sexually	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
k. Is sexually promiscuous	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
l. Talks excessively	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
m. Yells, screams or uses vulgar language	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
n. Does not understand or admit that he/she has any problems	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
o. Acts without thinking	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
p. Runs away or wanders away	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
q. Has difficulty setting goals	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
r. Has difficulty pursuing set goals	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
s. Has difficulty responding to feedback from supervisors or authority figures	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
t. Has difficulty in changing his/her behavior in response to feedback from supervisors or authority figures	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

	Never a Problem	Rarely a Problem	Sometimes a Problem	Often a Problem	Very Often a Problem
u. Laughs or cries for no apparent reason	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
v. Appears to have no interest in life	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
w. Acts as if he/she hears or sees people or things that aren't really there	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
x. Acts as if he/she is suspicious of others	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
y. Appears hyperactive or overactive	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
z. Has difficulty organizing leisure time	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
aa. Has difficulty paying attention or concentrating	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
bb. Has difficulty with learning new information	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
cc. Has difficulty remembering information from the past	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
dd. Has difficulty solving problems	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ee. Uses inappropriate social conversation when talking in a small group situation	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ff. Has trouble anticipating or recognizing the effects of his/her actions on others	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
gg. Appears to be depressed	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
hh. Appears to be anxious	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ii. Complains of being lonely	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
jj. Gets into difficulty or has problems when left alone at home	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
kk. Has difficulty making or keeping friendships	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

E. Service Needs

In this section of questions we would like to find out what services the head injured person has received and those that he/she needs.

El. In this next question we'd like to know what services the head injured person has applied for to get rehabilitation from the injury and what was the result of that application. Check whether or not you have applied for services from any of the following agencies. For each agency applied to, tell us on the next page whether the services were denied, given in the past, or are currently being given.

- |  |  |  |
|--|--|--|
| a. Mass. Rehabilitation Commission--<br>Independent Living Division            | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| b. Mass. Rehabilitation Commission--<br>Vocational Rehabilitation Division     | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| c. Mass. Commission for the Blind--<br>Independent Living Division             | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| d. Mass. Commission for the Blind--<br>Vocational Rehabilitation Division      | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| e. Mass. Dept. of Mental Health--<br>Mental Health Division                    | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| f. Mass. Dept. of Mental Health--<br>Mental Retardation Division               | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| g. Mass. Commission of the Deaf and<br>Hard of Hearing                         | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| h. Mass. Dept. of Social Services (DSS)  | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| i. Mass. Dept. of Public Health (DPH)  | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| j. Mass. Dept. of Youth Services (DYS)   | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| k. Mass. Dept of Education--<br>Special Education Division                     | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |
|  | ↓                                      |  |
| l. Bureau of Transitional Planning--<br>(Chapter 688--Turning 22 years of age) | 1 <input type="checkbox"/> Not applied | 2 <input type="checkbox"/> Yes-applied → |

E2. If the head injured person applied at this agency was he/she denied services, or did he/she receive services in the past but is not receiving them now, or is the head injured person currently receiving services from this agency?

- |    |                          |                                 |                                       |
|----|--------------------------|---------------------------------|---------------------------------------|
| a. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| b. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| c. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| d. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| e. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| f. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| g. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| h. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| i. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| j. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| k. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |
| l. | 1 [ ] Denied<br>Services | 2 [ ] Received<br>Past Services | 3 [ ] Currently<br>Receiving Services |



E3. For each type of service listed below indicate whether the head injured person has never needed this service, or currently needs this service but you don't know where to get it, or currently needs this service and you know where to get it, or is currently receiving this service, or has received this service in the past but no longer needs it.

	Never Needed	Needs but Need Information	Needs and Know Where to get it	Currently Receiving	Received in Past
a. Physical therapy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
b. Occupational therapy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
c. Speech or language therapy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
d. Psychotherapy or Psychological counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
e. Vocational assessment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
f. Pre-vocational training	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
g. Vocational training	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
h. Vocational counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
i. Vocational placement	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
j. Specialized mobility equipment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
k. Communication device	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
l. Home modifications such as ramps	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
m. Respite care (Short-term)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
n. Visiting nurse	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
o. Personal care attendant	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
p. Frequent medical follow-up	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
q. Special education services	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
r. Interpreter	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
s. Leisure or recreation services	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

	Never Needed	Needs but Need Information	Needs and Know Where to get it	Currently Receiving	Received in Past
t. Financial assistance	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
u. Family counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
v. Family training in behavior management	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
w. A day program for himself/herself	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
x. Transportation to programs for himself/herself	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

E3. Do you feel the head injured person is living in an appropriate setting right now?

1 [ ] Yes      2 [ ] No

E4. When you consider what type of living situation would be best for the head injured person in the future, how likely is it that he/she would need to live in the following types of residence?

	Not at all Likely	A Little Likely	Somewhat Likely	Very Likely
a. Community residence with live-in supervisory staff (24 hours)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
b. Community residence with part-time supervisory staff	1 [ ]	2 [ ]	3 [ ]	4 [ ]
c. Nursing Home or long-term care facility	1 [ ]	2 [ ]	3 [ ]	4 [ ]

CONTINUE ON TO NEXT PAGE PLEASE

E5. What additional information do you think is important for us to know as we make a report to the Massachusetts State Legislature about the rehabilitation needs of the head injured person?

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E6. Indicate below what your relationship is to the head injured person described in this survey.

- 1 [ ] You are the head injured person (SKIP THE NEXT QUESTION)
- 2 [ ] You are the legal guardian of the head injured person
- 3 [ ] You are another family member who is knowledgeable of the situation of the head injured person in your family.
- 4 [ ] You are someone else such as a friend or professional health care worker

E7. How long have you known the head injured person?

\_\_\_\_\_ Number of years and \_\_\_\_\_ Number of months

THANK YOU FOR YOUR PARTICIPATION IN THIS SURVEY. YOU HAVE MADE AN IMPORTANT CONTRIBUTION TO OUR PROJECT. PLEASE RETURN THE QUESTIONNAIRE IN THE ENCLOSED POSTAGE PAID ENVELOPE AS SOON AS POSSIBLE.

## APPENDIX B





NEEDS ASSESSMENT OF THE HEAD INJURED  
PROVIDER SURVEY

MASSACHUSETTS REHABILITATION COMMISSION  
STATEWIDE HEAD INJURY PROGRAM

AND

THE CENTER FOR SURVEY RESEARCH  
UNIVERSITY OF MASSACHUSETTS-BOSTON

Confidential: Information collected through this survey will not be used in any way which will identify individual persons.

## INSTRUCTIONS

### WHO SHOULD FILL OUT THE SURVEY?

Professionals who in the context of their jobs have as clients persons who have sustained traumatic head injuries.

### HOW TO FILL OUT THE SURVEY?

Indicate with an "X" your answer to each question. Many of the questions ask for average estimates for all of your head injured clients. You may have had some clients which you are no longer seeing. We would like your estimates to include these clients and their situation as of the last time you saw them. We recognize that you will not have exact information on these questions, but would like you to answer with your best professional estimates.

### ARE MY ANSWERS CONFIDENTIAL?

Yes in that we promise that no information you provide us will be used in any way which identifies you as an individual. Answers will be summarized across all providers in the survey, or major subgroups of providers.

### WHY SHOULD I PARTICIPATE?

You are part of a small sample of providers that we have asked to give us the benefit of their professional experience. If you don't respond, your experiences and the conditions of the clients you see, will not be represented in our report to the State Legislature.

It is very important that you respond as soon as possible. This will eliminate having to spend resources sending you reminders and also, therefore, we will have more time to prepare our report to the Legislature.

If you have any questions about filling out the questionnaire or the report that will be produced, you can call Debra Kamen at the Massachusetts Statewide Head Injury Program (617-727-8732) or Tom Mangione at the Center for Survey Research (617-956-1150).

A. Description of Your Practice

A1. What is your primary affiliation for your medical practice?

- |                                |  |
|--------------------------------|--|
| 01 [ ] An Acute Care Hospital  | 07 [ ] Out-Patient Clinic                      |
| 02 [ ] Tertiary Care Hopital   | 08 [ ] Nursing Home/Long-Term<br>Care Facility |
| 03 [ ] Community Hospital      | 09 [ ] Correctional<br>Institution             |
| 04 [ ] Psychiatric Hospital    | 10 [ ] Rehabilitation Program                  |
| 05 [ ] State Hospital          | 11 [ ] Private Practice                        |
| 06 [ ] Rehabilitation Hospital | 12 [ ] Other (Specify):<br>_____               |

A2. In what town and state is your primary affiliation located?

TOWN: \_\_\_\_\_ STATE: \_\_\_\_\_

A3. What is your discipline?

- 01 [ ] Physician (Specialty): \_\_\_\_\_
- 02 [ ] Psychologist/Neuropsychologist
- 03 [ ] Speech Pathologist
- 04 [ ] Occupational Therapist
- 05 [ ] Physical Therapist
- 06 [ ] Vocational Specialist
- 07 [ ] Recreational Therapist
- 08 [ ] Nurse
- 09 [ ] Respiratory Therapist
- 10 [ ] Nutritionist
- 11 [ ] Social Worker
- 12 [ ] Other (Specify) \_\_\_\_\_

A4. How many years of experience have you had in the field of head injury?

01 ☐ Less than 2 years

02 ☐ 2 to 5 years

03 ☐ 6 to 10 years

04 ☐ 11 to 15 years

05 ☐ 15 years or more

A5. Approximately what is the total number of traumatically head injured clients that you have ever treated or evaluated?

01 ☐ 25 or less

02 ☐ 26-50

03 ☐ 51-75

04 ☐ 76-100

05 ☐ Over 100

A6. Of all of these clients you have treated or evaluated, what proportion did you see in your private practice?

01 ☐ None

02 ☐ A Few (1-25%)

03 ☐ Some (26%-50%)

04 ☐ Many (51%-75%)

05 ☐ Most (76%-100%)

A7. Of all the head injured clients you have treated or evaluated, what proportion sustained a moderate to severe head injury?

00 ☐ None

01 ☐ 1%-10%

02 ☐ 11%-25%

03 ☐ 26%-50%

04 ☐ 51%-75%

05 ☐ 76%-100%

A8. Of all the head injured clients you have treated or evaluated, what proportion were in the following age groups?

a. Under 21 years old      b. 22 to 65 years old      c. Over 65 years old

00 [ ] None

00 [ ] None

00 [ ] None

01 [ ] 1%-10%

01 [ ] 1%-10%

01 [ ] 1%-10%

02 [ ] 11%-25%

02 [ ] 11%-25%

02 [ ] 11%-25%

03 [ ] 26%-50%

03 [ ] 26%-50%

03 [ ] 26%-50%

04 [ ] 51%-75%

04 [ ] 51%-75%

04 [ ] 51%-75%

05 [ ] 76%-100%

05 [ ] 76%-100%

05 [ ] 76%-100%

A9. What proportion of all your clients were insured through Medicaid or Medicare?

01 [ ] None

02 [ ] A Few (1-25%)

03 [ ] Some (26%-50%)

04 [ ] Many (51%-75%)

05 [ ] Most (76%-100%)

A10. What proportion of all your clients had private insurance coverage?

01 [ ] None

02 [ ] A Few (1-25%)

03 [ ] Some (26%-50%)

04 [ ] Many (51%-75%)

05 [ ] Most (76%-100%)



## B. Service Providers

B1. We'd like to get your views on the adequacy of service provided by a variety of state agencies with respect to their ability to meet the needs of your head injured clients. (a) Indicate for which agencies you have made referrals. (b) For each agency to which you have made referrals indicate whether the agency was able to provide adequate or appropriate services or not. (c) If the agency was not able to provide adequate services indicate your opinion as to the major reason why.

	<u>a. Made Referrals?</u>		<u>b. Services Provided Were:</u>	
a. Mass Rehab Commission's				
(1) Independent Living Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
(2) Vocational Rehab Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
(3) Homemaker/Chore Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
(4) Personal Care Attendant Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
(5) Statewide Head Injury Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
b. Mass Commission for the Blind's				
(1) Independent Living Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
(2) Vocational Rehab Program	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
c. Department of Mental Health	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
d. Department of Mental Retardation	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
e. Mass Commission of the Deaf and Hard of Hearing	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
f. Department of Social Services	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
g. Department of Public Health	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
h. Department of Youth Services	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
i. Office for Children	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate
	↓			
j. Department of Education-- Special Education	1[ ] No	2[ ] Yes	1[ ] Adequate	2[ ] Inadequate

Definitions for use in responding to "c" below:

Fiscal resources: Inadequate budget to deliver needed services.

Staff: Insufficient numbers of staff within the agency.

Clinical Expertise: Agency staff inadequately trained with respect to the needs of the head injured.

Appropriate Services: Agency does not offer services specifically for head injured clients or needs to develop additional services.

c. Reason agency failed to provide adequate services was their lack of:

	<u>Fiscal Resources</u>	<u>Staff</u>	<u>Clinical Expertise</u>	<u>Appropriate Service</u>
a(1)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
a(2)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
a(3)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
a(4)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
a(5)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
b(1)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
b(2)	1 [ ]	2 [ ]	3 [ ]	4 [ ]
c.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
d.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
e.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
f.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
g.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
h.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
i.	1 [ ]	2 [ ]	3 [ ]	4 [ ]
j.	1 [ ]	2 [ ]	3 [ ]	4 [ ]

C. Needs of Head Injured

C1. Of all of your head injured clients, what proportion of them exhibited the following conditions at some point after their injury?

	None <u>0*</u>	A Few <u>1-25*</u>	Some <u>26-50*</u>	Many <u>51-75*</u>	Most <u>76-100*</u>
a. Mild behavioral dysfunction	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
b. Moderate to severe behavioral dysfunction	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
c. Mild communication disorder	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
d. Moderate to severe communication disorder	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
e. Mild visual impairment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
f. Moderate to severe visual impairment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
g. Mild cognitive impairment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
h. Moderate to severe cognitive impairment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
i. Had an active substance abuse	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
j. Were arrested for criminal behavior	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
k. Psychiatric disorder	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
l. Had medical problems requiring frequent follow-up	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

C2. Of all the head injured clients you have treated or evaluated, what proportion exhibited the following at the time you stopped seeing them (or as of now for current clients)?

	<u>None</u> <u>0%</u>	<u>A Few</u> <u>1-25%</u>	<u>Some</u> <u>26-50%</u>	<u>Many</u> <u>51-75%</u>	<u>Most</u> <u>76-100%</u>
a. Attained independence in activities of daily living.	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
b. Attained independence in mobility.	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
c. Were able to live in the community independently	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
d. Were still wheelchair bound	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
e. Were able to be employed competitively	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

C3. For each of the services listed below indicate what proportion of your clients needed the service but did not receive them (at all or not in Massachusetts).

	<u>None</u> <u>0%</u>	<u>A Few</u> <u>1-25%</u>	<u>Some</u> <u>26-50%</u>	<u>Many</u> <u>51-75%</u>	<u>Most</u> <u>76-100%</u>
a. Physical Therapy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
b. Occupational Therapy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
c. Speech/language Therapy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
d. Psychotherapy/Psychological Counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
e. Peer Counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
f. Training in Independent Living Skills	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
g. Vocational Assessment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
h. Pre-vocational Training	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
i. Vocational Counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
j. Vocational Training	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
k. Vocational Placement	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
l. Specialized Mobility Equipment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
m. Mobility Training	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]



n. Communication Device	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
o. Motor Vehicle Modifications	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
p. Home Modifications (e.g. ramps)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
q. Other Adaptive equipment	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
r. Respite Care	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
s. Visiting Nurses	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
t. Personal Care Attendant	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
u. Frequent Medical Follow-up	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
v. Special Education Services	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
w. Interpreter	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
x. Leisure/Recreation Services	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
y. Financial Assistance	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
z. Family Counseling	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
aa. Family Training in Behavioral Management	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
bb. Day Program (full-time)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
cc. Day Program (Part-time)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
dd. Transportation	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ee. Homemaker/Chore Assistance	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ff. Legal Assistance	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
gg. Community residence with live-in supervisory staff (24 hrs.)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
hh. Community residence with part-time supervisory staff	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ii. Cooperative Living Apartment (Staff accessible by client)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
jj. Nursing home or long-term care facility	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
kk. Case management	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
ll. Individual advocacy	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]



C4. What proportion of your clients have a current (or last known) living situation that was inappropriate for them?

<u>None</u> <u>0%</u>	<u>A Few</u> <u>1-25%</u>	<u>Some</u> <u>26-50%</u>	<u>Many</u> <u>51-75%</u>	<u>Most</u> <u>76-100%</u>
1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

C5. Indicate the proportion of your clients for whom each of the following types of residential options would be appropriate?

	<u>None</u> <u>0%</u>	<u>A Few</u> <u>1-25%</u>	<u>Some</u> <u>26-50%</u>	<u>Many</u> <u>51-75%</u>	<u>Most</u> <u>76-100%</u>
a. Independent (Unsupervised) Living	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
b. Living at home with Family	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
c. Partial Supervision (Apartment or Community Residence)	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
d. 24-Hour Supervised Community Residence	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]
e. Long-Term Care Facility	1[ ]	2[ ]	3[ ]	4[ ]	5[ ]

C6. What additional information do you think is important for us to know as we make a report to the Massachusetts State Legislature about the rehabilitation needs of the head injured person?

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Thank you for your input to our report to the state legislature. Your efforts will help provide better services for the head injured. Please return the questionnaire as soon as possible in the enclosed postage paid envelope.

1. The first part of the paper discusses the importance of understanding the underlying mechanisms of the observed phenomena. This is crucial for developing effective interventions and policies.

2. The second part of the paper focuses on the methodological aspects of the study. It describes the data collection process, the statistical models used, and the validation procedures.

3. The third part of the paper presents the results of the analysis. It shows that there is a significant positive correlation between the variables of interest, which supports the hypothesis.

4. The fourth part of the paper discusses the implications of the findings. It suggests that the results have important implications for both theory and practice, and provides recommendations for future research.

5. The fifth part of the paper concludes the study. It summarizes the main findings and reiterates the importance of the research. It also acknowledges the limitations of the study and offers suggestions for further exploration.

6. The final part of the paper is a reference list, which includes all the sources cited in the text. This list is organized alphabetically by the author's name.

Appendix C				
Table C.1				
Description of the data				
Table C.2				
Table C.3				
Table C.4				
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## APPENDIX C

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Current Living Setting by Sample Type

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AGE AND SAMPLE TYPE	Living Situation			
	N's	HOUSE/ APARTMENT	HOSPITAL	LONG-TERM CARE FACILITY
<u>SHIP CLIENTS</u>				
Under 19	15	60%	13%	27%
19-29	170	67	11	22
30-39	70	71	13	16
40+	34	62	6	32
<u>MASS Chapter</u>				
Under 19	18	94	0	6
19-29	86	82	9	9
30-39	72	79	8	13
40+	80	82	9	9
<u>UMASS</u>				
Under 19	144	100	0	0
19-29	129	95	3	2
30-39	48	98	0	2
40+	77	97	0	3





## APPENDIX D



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Characteristics of Head Injury Clients  
Reported by Providers

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Proportion with Moderate to Severe Head Injury	64%
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Age\*

Proportion under 21	28%
Proportion 22-65	55%
Proportion over 65	5%

Source of Payment

Proportion of clients with Medicaid or Medicare	43%
--	-----

Proportion with private insurance	40%
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\* Total is less than 100% due to independent estimations and averaging calculations.





## APPENDIX E



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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
NEURO-BEHAVIORAL PROBLEMS			
a. Threatens to injure others			
Never	75%	86%	91%
Rarely	21	11	7
Often, Very Often	4	3	2
b. Assaults others physically			
Never	84%	90%	94%
Rarely	13	8	5
Often, Very Often	3	2	1
c. Threatens to destroy property			
Never	86%	89%	93%
Rarely	11	8	5
Often, Very Often	3	3	2
d. Destroys property			
Never	89%	92%	96%
Rarely	8	6	3
Often, Very Often	3	2	1
e. Threatens to injure self			
Never	82%	89%	96%
Rarely	11	8	3
Often, Very Often	7	3	1

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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
NEURO-BEHAVIORAL PROBLEMS (Con't)			
f. Injures himself/herself purposely			
Never	92%	96%	98%
Rarely	5	3	2
Often, Very Often	3	1	0
g. Yells, screams or uses vulgar language			
Never	67%	73%	85%
Rarely	24	14	10
Often, Very Often	9	13	5
h. Runs or wanders away			
Never	82%	90%	97%
Rarely	11	7	2
Often, Very Often	7	3	1
PERSONALITY DISORDERS			
a. Touches or molests others sexually			
Never	93%	98%	99%
Rarely	5	2	1
Often, Very Often	2	0	0

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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
PERSONALITY DISORDERS (Con't)			
b. Exposes self sexually			
Never	95%	99%	99%
Rarely	4	1	1
Often, Very Often	1	0	0
c. Is sexually promiscuous			
Never	94%	94%	98%
Rarely	4	3	1
Often, Very Often	2	3	1
d. Talks excessively			
Never	71%	73%	91%
Rarely	16	18	5
Often, Very Often	13	9	4
e. Acts without thinking			
Never	44%	54%	81%
Rarely	29	27	14
Often, Very Often	27	19	5
f. Laughs or cries for no apparent reason			
Never	77%	74%	89%
Rarely	15	17	7
Often, Very Often	8	9	4



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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
PERSONALITY DISORDERS (Con't)			
g. Acts as if he/she hears or sees people or things that aren't really there			
Never	88%	91%	98%
Rarely	8	4	2
Often, Very Often	4	5	0
h. Acts as if he/she is suspicious of others			
Never	74%	81%	92%
Rarely	15	13	5
Often, Very Often	11	6	3
i. Appears hyperactive or overactive			
Never	79%	81%	88%
Rarely	11	10	6
Often, Very Often	10	9	6
NEURO-PSYCHIATRIC PROBLEMS			
a. Appears to have no interest in life			
Never	61%	61%	89%
Rarely	20	23	8
Often, Very Often	19	16	3

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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
NEURO-PSYCHIATRIC PROBLEMS (Con't)			
b. Uses inappropriate social conversation when talking in a small group situation			
Never	54%	68%	91%
Rarely	26	18	6
Often, Very Often	20	14	3
c. Appears to be depressed			
Never	48%	46%	81%
Rarely	29	23	11
Often, Very Often	23	21	8
d. Appears to be anxious			
Never	55%	53%	82%
Rarely	27	28	11
Often, Very Often	18	19	7
e. Complains of being lonely			
Never	50%	58%	82%
Rarely	26	20	10
Often, Very Often	24	22	8

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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)

NEURO-PSYCHIATRIC PROBLEMS (Con't)

- f. Has difficulty making or  
keeping friendships

Never	52%	55%	90%
Rarely	17	17	6
Often, Very Often	31	28	4

COGNITIVE PROBLEMS

- a. Does not understand or  
admit that he/she has any  
problems

Never	52%	62%	87%
Rarely	26	18	8
Often, Very Often	22	20	5

- b. Has difficulty responding  
to feedback from supervisors  
or authority figures

Never	46%	50%	86%
Rarely	23	23	8
Often, Very Often	31	27	6

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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
COGNITIVE PROBLEMS (Con't)			
c. Has difficulty in changing his/her behavior in response to feedback from supervisors or authority figures			
Never	47%	51%	87%
Rarely	24	22	8
Often, Very Often	29	27	5
d. Has difficulty organizing leisure time			
Never	34%	43%	84%
Rarely	19	26	9
Often, Very Often	47	31	7
e. Has difficulty paying attention or concentrating			
Never	27%	30%	77%
Rarely	31	30	14
Often, Very Often	42	40	9
f. Has difficulty with learning new information			
Never	28%	32%	83%
Rarely	26	27	11
Often, Very Often	46	4	6

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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
COGNITIVE PROBLEMS (Con't)			
g. Has difficulty remembering information from the past			
Never	40%	44%	80%
Rarely	25	23	13
Often, Very Often	35	33	7
h. Has difficulty solving problems			
Never	27%	37%	83%
Rarely	30	26	11
Often, Very Often	43	37	6
i. Gets into difficulty or has problems when left alone at home			
Never	66%	83%	94%
Rarely	15	8	4
Often, Very Often	19	9	2
j. Has trouble anticipating or recognizing the effects of his/her actions on others			
Never	39%	49%	86%
Rarely	23	25	8
Often, Very Often	38	26	6



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Current Impairment Indicators by  
Sample Type

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LEVEL OF IMPAIRMENT EXPERIENCED GROUPED BY TYPE OF IMPAIRMENT	Sample Type		
	SHIP CLIENTS (N=317)	MASS CHAPTER (N=281)	UMASS (N=438)
COGNITIVE PROBLEMS (Con't)			
k. Has difficulty setting goals			
Never	32%	49%	84%
Rarely	17	25	9
Often, Very Often	51	36	7
l. Has difficulty pursuing set goals			
Never	28%	36%	84%
Rarely	21	27	8
Often, Very Often	51	37	8
SUBSTANCE ABUSE PROBLEMS			
a. Currently abuses alcohol			
Never	83%	88%	92%
Rarely	7	7	4
Often, Very Often	6	5	4
b. Currently abuses drugs			
Never	90%	94%	97%
Rarely	6	3	2
Often, Very Often	4	3	1



## APPENDIX F



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## Type of Services Needed For Total Surveyed

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### Unmet Needs

Type of Service by Sample Type	Lack of Information	Hasn't Sought Yet	Unaware of Need*	Total Unmet
a. Physical Therapy	59%	4%	3%	7%
b. Occupational Therapy	45	6	2	8
c. Speech or Language Therapy	45	4	1	5
d. Psychotherapy or Psychological Counseling	42	8	4	12
e. Vocational Assessment	27	11	4	15
f. Pre-vocational Training	15	11	4	15
g. Vocational Training	14	14	5	19
h. Vocational Counseling	16	14	5	19
i. Vocational Placement	9	16	5	21
j. Special Mobility Equipment	18	2	2	4
k. Communication Device	5	2	1	3
l. Home Modifications	10	3	1	4
m. Respite Care	9	5	2	7
n. Visiting Nurse	19	2	1	3
o. Personal Care Attendant	15	3	2	5
p. Frequent Medical Follow-up	44	4	6	10
q. Special Education	20	9	3	12
r. Interpreter	1	0	1	1
s. Leisure or Recreational Services	12	19	4	23
t. Financial Assistance	32	14	4	18
u. Family Counseling	23	10	6	16
v. Family Training in Behavioral Management	12	12	3	15
w. Day Program	15	15	2	17
x. Transportation to Programs	19	14	4	18

\*"Unaware of Need" are persons who, based on their survey data, would probably need services but who do not report needing services. Not available or determinant for all services.





## APPENDIX G



### Acronyms

ADL	- Activities of Daily Living
ALS	- Advanced Life Support
BLS	- Basic Life Support
CARF	- Commission on Accreditation of Rehabilitation Facilities
CHI	- Closed Head Injury
CNS	- Central Nervous System
DMH	- Department of Mental Health
DON	- Determination of Need
DRG	- Diagnostically Related Groups
EMT	- Emergency Medical Treatment
GAO	- General Accounting Office
ICD	- International Code of Diseases
ICF	- Intermediate Care Facility
IIHS	- Insurance Institute for Highway Safety
LTCF	- Long-Term Care Facility
Mass. Chapter	- Massachusetts Chapter of the National Head Injury Foundation
PTA	- Post-Traumatic Annesia
PVS	- Persistent Vegetative State
SCIPP	- Statewide Comprehensive Injury Prevention Program
SHIP	- Statewide Head Injury Program
SNF	- Skilled Nursing Facility
TBI	- Traumatic Brain Injury
UHDDS	- Uniform Hospital Discharge Data Set
UMASS	- University of Massachusetts Medical/Trauma Center
VNA	- Visiting Nurses Association







